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Global norms-domestic practice

**The role of community-based organisations in
the diffusion of HIV and human rights norms**

**Enrique Restoy, PhD Thesis
Department of International Relations
University of Sussex
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I hereby declare that this thesis has not been and will not be submitted in whole or in part to another University for the award of any other degree.

Signature:

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ABSTRACT:

International norms are central to international relations because they constitute key instruments to influence state behaviour (Finnemore and Sikkink, 1998; Risse and Sikkink, 1999; Acharya, 2004). The process by which international norms, principles and procedures diffuse into national systems is called norm diffusion (Krook and True, 2010; Towns, 2012; Brown, 2014). This thesis contributes to our understanding of the complexities of norm diffusion processes by undertaking the first in-depth analysis of the role that community-based organizations (CBOs) play in such processes. Focusing on the area of global health norms regarding HIV/AIDS, and based on extensive field research undertaken in Honduras, Ukraine, Uganda, and El Salvador, the thesis presents evidence of the CBOs analysed playing various essential roles in the diffusion of international norms domestically. First, they may act as implementers of such norms ensuring their appropriation among the populations they represent and generating local practice, on occasion even bypassing their own governments when these have rejected such norms. Second, CBOs may also be able to influence their governments and other relevant state actors at the later stages of norm diffusion, when states are deemed to implement international norms through their integration into national practice, even to the point of making states change their stated positions on certain international norms. Thirdly, through the simultaneous interaction with and entanglement in multiple norm diffusion processes, CBOs may also be able to alter such processes by tactically interlinking them and affecting their respective outcomes.

LIST OF ABBREVIATIONS

ACT UP	AIDS Coalition to Unleash Power
AIDS	Acquired immune deficiency syndrome
ARV	Antiretroviral drugs or therapy
CAT	UN Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment
CBO	Community-Based Organisation
CCM	Country Coordinating Mechanism
CND	Commission on Narcotic Drugs
DFID	Department of International Development- United Kingdom
DPA	Drug Policy Alliance
ENEY	Drug Users Anonymous, Ukraine
FARUG	Freedom and Roam Uganda
FCO	Foreign and Commonwealth Office-United Kingdom
Global Fund	Global Fund to Fight AIDS, Tuberculosis and Malaria
HIV	Human immunodeficiency virus
HRW	Human Rights Watch
IACHR	Inter-American Commission on Human Rights
ICCPR	International Covenant on Civil and Political Rights
ICDP	International Commission on Drug Policy
ICESCR	International Covenant on Economic, Social and Cultural Rights
IHAA	International HIV/AIDS Alliance
IHR	International Health Regulations
INCB	International Narcotics Control Board
IR	International Relations

ISSS	<i>Instituto del Seguro Social de El Salvador</i> (Salvadoran Social Security Institute)
LGBTI	Lesbian, Gay, Bisexual, Transgender and Intersex
MSM	Men who have sex with men
NGO	Non-Governmental Organisation
OAS	Organisation of American States
OHCHR	United Nations Office of the High Commissioner for Human Rights
OSI/F	Open Society Institute/Foundation
OST	Opiates Substitution Therapy
PEPFAR	United States' President Emergency Plan for AIDS Relief
PDU	People who use drugs
SARS	Severe acute respiratory syndrome
SIMETRISS	<i>Sindicato de Médicos Trabajadores del Instituto Salvadoreño del Seguro Social</i> , Medical Trade Union of El Salvador
SMT	Substitution Maintenance Therapy/ Treatment
SMUG	Sexual Minorities Uganda
SW	Sex worker
TAC	Treatment Action Campaign
TAN	Transnational Advocacy Network
TASO	The AIDS Support Organisation
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNDP	United Nations Development Programme
UNGA	United Nations General Assembly
UNGASS	United Nations General Assembly Special Session
UNODC	United Nations Office on Drugs and Crime
WHO	World Health Organisation

1. INTRODUCTION, STRUCTURE AND RESEARCH METHODOLOGY

Introduction

Over the past 20 years, scholars, decision makers and other observers have studied the relationship between the generation of norms at the international level and their adoption and incorporation into national practice by states (Finnemore and Sikkink, 1998; Risse and Sikkink, 1999; Acharya, 2004). This analysis, referred to in literature as norm diffusion, can be defined as the framework whereby international norms, values, principles and procedures in a given discipline diffuse into national systems. International norms emanate from values or principles shared by a considerable number of states and international actors and to which these states show a commitment to implement (Wiener, 2009; Krook and True, 2010; Brown, 2014). This commitment underpins a correlation between the generation of international norms and the acceptance (referred to as appropriation) of such norms by states and their integration by state actors into the national practice of such states (Krook and True, 2010; Brown, 2014). The analysis of norm diffusion is pivotal in international relations (IR) theory since it studies the pathways international norms take until they reach those they are intended to, providing essential information as to how these norms evolve and crucially, how they influence state behaviour, central in the analysis of IR. The study of norm diffusion is “essential to develop a better understanding of the nature and evolution of this key element of international policy making” (Stoeva, 2010:1).

There are three key areas of the theoretical debate around the generation of international norms and their translation domestically to which this thesis contributes. Firstly, there is a distinction between the consideration of norms as static elements as they travel from their generation to their adoption by states on one hand (Nadelmann, 1990; Florini, 1996; Risse and Sikkink, 1999), and, on the other hand, the consideration of international norms as evolving themselves as they spread (Acharya, 2004) in dynamic processes of diffusion of norms (Krook and True, 2010). Secondly, there is a clear differentiation between analyses of international norms centred on the behaviour of states as norm champions, opponents and takers (Finnemore and Sikkink, 1998; Stoeva, 2010), and those which broaden their study to include the role other actors play, particularly the influence of transnational advocacy networks (TANs) at the time where norms are generated and negotiated prior to being appropriated (accepted) by states (Keck and Sikkink, 1998; Risse and Sikkink, 1999; Hertel, 2006). TANs refer to the struc-

tured interaction in networks of non-state actors in international politics, including international and national NGOs, but also social movements, the media, religious institutions, and even parts of intergovernmental organisations and parts of state structures such the executive or the legislative (Keck and Sikkink, 1998).

Thirdly, the majority of the analysis of norm diffusion focuses on the process that takes place at the international level, when norms are proposed and socialised through a negotiation that leads to the state appropriation and adoption of an international norm and its eventual incorporation into national practice (Risse and Sikkink, 1999; Davis, 2000; Stoeva, 2010; Towns, 2012). However, there is an important part of literature which studies what takes place when principles of international norms meet with the realities of domestic conditions (Stevenson, 2013; Brown, 2014), when states adapt an international norm that they have appropriated before domesticating it so that it conforms to the local reality in which the state operates in a process referred to as localisation (Acharya, 2004). Authors from other areas of IR literature focus on how local actors, with a particular emphasis on non-governmental organisations, appropriate and adapt internationally generated norms to their local context in a process referred to as vernacularisation (Merry, 2009; Levitt and Merry, 2009; Orr, 2012).

This thesis furthers this particular analysis on the complexities surrounding the impact of norms on domestic practice. This term includes not only national practice (the compliance with and enforcement of international norms by government structures and other state actors such as the judiciary, which is an essential notion in norm diffusion literature) but also of local practice (carried out by all relevant actors, including non-state actors). The thesis argues that current norm diffusion-related debates have paid insufficient attention to the significant role that local actors other than state actors may play in influencing the process by which international norms are incorporated into national practice. Local actors may also play a role in generating local practice themselves through their own embracing and implementation of international norms thus contributing to the domestic practice of international norms even when the government and relevant state structures reject such international norms.

If the ultimate goal in the analysis of international norms is indeed to understand how these norms translate into the local realities within states, without the analysis of which and how actors intervene in such translation, any reflection on the analysis of norm diffusion is inevitably incomplete and potentially distorted. Yet current literature does not consider in detail four crucial elements to help understand the journey of international norms: 1) What ac-

tors other than state structures and entities contribute to the generation of domestic practice based on international norms? 2) What influences the behaviour of governments and other relevant state actors at the local level of norm implementation once they have committed to, localised or rejected an international norm? 3) Which circumstances make governments reposition themselves in relation to an international norm prompting them to modify their previously stated positions in relation to an international norm? 4) How does domestic practice (local and national) in relation to one norm diffusion process affect the outcomes of other related norm diffusion processes?

In order to contribute to answering these questions, the thesis explores global health norms as a complement to the extensive corpus of literature on the diffusion of human rights norms (Keck and Sikkink, 1998; Risse and Sikkink, 1999; Krook and True, 2010; Stoeva, 2010). Global health matters to all of us. It impacts on the health outcomes of millions of people and communities and therefore occupies an important space in the study of IR (Fidler, 2010; Wolff, 2012; Brown, 2014). Global health norms can be defined as rules, agreements, commitments and guidelines established or promoted by “states, intergovernmental organisations and non-state actors to deal with challenges to health that require cross-border collective action to address effectively” (Fidler, 2010: 3, Youde, 2012, Harman 2012). These norms may reflect a myriad of approaches organised by a wide range of state and non-states actors, illustrating the complex and often chaotic context of global health governance (Harman, 2012).

Global health norms approaches have traditionally been based on biomedical considerations, but other approaches have emerged including considering health from a security point of view, treating inequity as a key objective of global health norms, putting the right to health and related international human rights norms and principles at the centre of global health interventions, or treating global health as an element of political economy or biopolitics (Sen, 1992; Hunt, 2002; Elbe, 2005). Often, these approaches lead to opposing norms regulating a given global health issue reflecting tensions and competing and differing discourses on health which states need to choose from when carrying out their public health interventions (Harman, 2012). For example, a country may decide to provide treatment of all people living with hepatitis C residing in it regardless of their immigration status upholding the right to health for every person within its jurisdiction or for biomedical reasons, to avoid transmission to the rest of the population. But it could also choose to deny this treatment on economic grounds given the high price of these medicines, or for political or security reasons to avoid sending a message of being open to illegal immigration.

Global health norms also have two significant characteristics that add richness to the analysis of the role of non-state actors in norm diffusion that this thesis undertakes. Firstly, they can range from the highly regulative nature of International Health Regulations (IHR) governing the global system of disease surveillance and control (Davies et al., 2015) to far less regulative norms such as WHO guidance on good practice, giving more room for states to adapt them to fit into their local contexts (Youde, 2012; Kamradt-Scott, 2012). Secondly, global health, as opposed to earlier models of cross-border health cooperation, is unique in explicitly recognising that “states are not the only relevant actors for addressing health concerns” (Youde, 2012:3). There is an important role for actors other than the state in the implementation of global health norms within global health governance, particularly community-based organisations (CBOs) at the level of primary health care (Reza-Paul et al., 2008; Campbell and Cornish, 2010; Mburu et al., 2012), making these actors particularly relevant in the analysis of the translation of global health norms domestically. CBOs can be defined by three main common characteristics which are applicable to all the CBOs considered in this thesis irrespective of their degree of organisational development in terms of resources, governance or management structures: they are non-for-profit organisations, they are mostly formed of and managed by members of the community or population they represent, and they exist to provide services to and/or represent such community or population (Chechetto-Salles and Geyer, 2006).

Within global health, global HIV/AIDS governance where international HIV norms provides a fertile ground to study the interrelation between the diffusion of international human rights norms and global health norms as the global HIV response is arguably also the most ambitious and coordinated effort to date to establish the link between health and human rights (Piot, et al., 2009). Human rights-based HIV norms underpin the human rights-based approach to the global HIV response. These norms are based on three main pillars: 1) international human rights standards and political commitments made by governments in relation to the HIV response, for example, the right to health enshrined in the International Covenant on Economic, Social, and Cultural Rights (ICESCR, 1966), and in the United Nations General Assembly Political Declaration on HIV and AIDS (UNGA, 2011) (see Appendix 3); 2) human rights-based principles of behaviour for actors involved in the HIV response, for example, equal access or accountability of duty bearers; 3) the application of a set of specific interventions aimed to improve the human rights context of people at higher risk of HIV, for example, legal counselling for people living with HIV victims of discrimination (Clayton et al.,

2014). However, tensions and contradictions among approaches in global health also apply to the response to the HIV/AIDS pandemic. On many occasions national practice to respond to HIV/AIDS is not human rights-based. For example, some countries carry out compulsory HIV testing to foreigners, denying entry to those living with HIV in order to contain the spread of the disease domestically while other countries uphold freedom of movement without discrimination based on HIV status and the right to informed and voluntary consent to HIV testing as basic human rights-based HIV norms.

The empirical analysis of this thesis focuses on the role of CBOs made of and representing populations at higher risk of HIV in influencing the diffusion of human rights norms within the diffusion of HIV norms. The reasons for furthering the analysis of CBOs are multiple and significant. From a theoretical analysis point of view, the study of the role CBOs play in the diffusion of HIV norms helps fill the critical gap in IR theory described earlier as to the role of actors other than states in the impact of international norms on domestic (local and national) practice. Furthermore, the analysis of the simultaneous positioning of CBOs on norm diffusion processes within global HIV/AIDS governance on one hand, and the international human rights system on the other, sheds light as to how these governance systems interlink with each other providing further elements of analysis for those interested in studying either or both.

It is important to fill this gap and understand the role and positioning of actors such as CBOs who are both part of the diffusion of norms and those for whom these norms are intended. Both the international human rights and the global health governance systems exist to improve the lives of people and communities not merely to regulate their behaviour. As far as the international HIV response is concerned, this moral imperative translates into the need to study the effectiveness of policies for the care of millions of people living with HIV and the prevention of HIV transmission to millions more. Considering that the HIV response is largely regulated by international norms (Elbe, 2009; Nguyen, 2010; Seckinelgin, 2012), but implemented to a large degree by CBOs of those affected by HIV (Glynn et al., 2008; Sarkar, 2010; Restoy and Teltschik, 2014), it is crucial to analyse what these norms and the organisations on which a large portion of the success in ending AIDS rests mean to each other. Lessons in this regard would not only help understand and improve policies to respond to end AIDS, but many other current and pressing global health threats.

These imperatives inform the central research question of this thesis: what role can

CBOs of people at higher risk of HIV play in the diffusion of human rights-based HIV norms domestically? The main points of analysis associated with this central question focus on provision of empirical evidence as to: 1) whether the CBOs studied in the thesis can generate their own local practice based on their embracing of human rights-based HIV norms; 2) whether these CBOs can influence positions of some key external and/or internal actors regarding the diffusion of certain international HIV and human rights norms; and 3) what lessons can be learned about the interrelation between international norms as a result of analysing the strategies by the CBOs studied to try to influence various norm diffusion processes simultaneously. The findings of the empirical chapters of this thesis provide three major original contributions to the study of international norms as they translate into domestic practice worth further analysis in IR literature underpinning the need for further research and exploration in IR literature as to the role CBOs at higher risk of HIV play in the diffusion of international norms domestically.

First, the thesis demonstrates that the CBOs of people at higher risk of HIV studied ensure the ownership of international human rights norms among the populations they represent and generate local practice through their interventions to respond to HIV basing them on such international norms. This finding makes a direct connection between the role of CBOs in norm diffusion and vernacularisation theory, which highlights the role of local organisations in adopting and localising international norms but does not analyse how such role translate into domestic practice (Merry, 2009; Orr, 2012). However, in the particular case of CBOs of people at higher risk of HIV studied in the field research, the appropriation of international norm is indeed more straightforward and takes far less adaptation to the local context than vernacularisation authors suggest (Levitt and Merry, 2009). The thesis offers an explanation for this finding: since the populations represented by the CBOs of people at higher risk of HIV analysed in the thesis are highly discriminated against and pushed out of local social structures, these CBOs tend to embrace those international norms which challenge the status quo the most. Some of organisations analysed in the thesis incorporate such norms into their local practice of implementation of HIV responses to the point of bypassing their own governments opposing such norms. They also place such norms at the core of their strategies to contribute to and influence government-led national practice in relation to its response to HIV and its human rights obligations.

Second, the thesis demonstrates that with their active involvement in norm diffusion processes, some of the CBOs analysed in the thesis may indeed be able to influence key

external and internal actors, including governments and relevant state structures and entities to the point of overturning the original positioning of these actors towards certain norms. This finding is consistent with dynamic interpretations of how international norms are integrated into national practice in processes that can lead to the adaptation of these norms by states (Acharya, 2004; Krook and True, 2010; Brown, 2014). CBO's influence over state actors could continue after the relevant state representatives have committed the state to implementing a particular norm or when they have rejected or modified it. The case studies in the thesis show that indeed governments and relevant state actors constantly change their positions in relation to international norms even after they have committed the state to adopt or reject such norms.

The thesis therefore provides evidence from the case studies of CBOs playing critical roles in the domestic practice of international norms, both through their own interventions (local practice) providing their own services and interventions based on such norms, and when influencing the behaviour of governments and key state structures and actors (national practice) regarding international norms. Across the case studies, this contribution to national practice includes playing a recognised role by state actors and/or relevant external actors as contributors to the national response to HIV and influencing relevant external or local actors or both sets of actors.

Thirdly, the analysis of the field research in this thesis makes an original contribution to the study of interaction between various norm diffusion processes which is lacking in literature debates. Some of the CBOs studied in the thesis attempt to influence several norm diffusion processes affecting the populations they represent, in particular in relation to international HIV and human rights norms, by affecting either the behaviour of state actors at the level of norm implementation (when state actors comply and enforce an international norm they have appropriated), or making relevant state actors revisit their own positions in relation to a particular international norm. This interaction between processes is largely possible as some of the CBOs studied strategize according to the state structure they need to influence. This in fact contradicts the widespread assumption in literature that states act as one single actor in the diffusion of international norms (Nadelmann, 1990; Cortell and Davis, 2000; Stoeva, 2010).

States in the case studies of this thesis are inconsistent in their positions regarding various norm diffusion processes, for instance, when committing to implementing international norms on human rights-based responses to HIV among sexual minorities while

rejecting human rights norms against discrimination based on sexual orientation or gender identity. This is due to the fact that the actors at different levels of hierarchy representing the state vary from one norm diffusion process to another depending on which international governance system each process belongs to. The prominence of one governance system over another when they contain norms that contradict each other is demonstrated when the state effectively complies with and enforces one of the competing international norms instead of the other reflecting the level of hierarchy of the governance system to which each norm belongs. In the previous example of sexual minorities, it is often health authorities who commit to adopting HIV norms based on non-discrimination based on sexual orientation, while other parts of government (ministries of justice, interior, religious affairs, etc....) promote policies further persecuting this population which often render these rights-based HIV responses among sexual minorities ineffective.

Chapter structure and research methodology

After this introductory chapter summarising the content of the thesis and the main contributions it makes, the thesis presents the theoretical framework of norm diffusion and related literature on the process whereby international norms are translated into domestic (local and national) practice. The theoretical framework chapter analyses more specifically literature of relevance in the analysis of the diffusion of international HIV norms, with a particular emphasis on debates and gaps in the analysis of the role of CBOs of populations affected by HIV in the diffusion of human rights-based HIV norms. This is followed by a short discussion chapter on the main areas of empirical research this thesis explores, and which is presented in four case studies.

The case studies present the findings of field research following an induction analysis undertaken in four lower or middle income countries between 2011 and 2013 among CBOs of people affected by HIV. Although the HIV/AIDS epidemic has most impacted on low income countries, particularly in Sub-Saharan Africa, it is in middle income countries where the burden of HIV (57% of people living with HIV in the World) is concentrated. Out of the roughly 15 million people living with HIV who do not have access to antiretroviral (ARV) treatment, about two thirds live in middle income countries.¹ The populations chosen for the case studies all belong to so called key populations at higher risk of HIV exposure (referred to throughout the thesis as populations at higher risk of HIV), understood as those who are most likely to be

¹ World Bank, 'Middle income countries', www.worldbank.org/en/country/mic, accessed on 2 August, 2015.

exposed to HIV or to transmit it combined with reduced access to services and are particularly vulnerable to human rights violations for being criminalized or otherwise marginalized (UNAIDS, 2012a; International Commission on HIV and the Law, 2012; Global Fund, 2014). Given the high level of stigma and discrimination associated with being HIV positive, “in all countries key populations include people living with HIV” (UNAIDS, 2011:18). In most settings men who have sex with men, transgender persons, people who inject drugs, and sex workers are among these populations (UNAIDS, 2011).

The case study selection follows three main criteria to ensure wide representation and comparison: populations’ representation, geographic scope and variety of organisational development of the CBOs studied. These criteria permit to focus on the roles of these CBOs in relation to international norms minimising any possible analysis contamination by other relevant factors such as the epidemiological context of the countries where these CBOs operate, the weight of external actors, such as international donors, in the domestic HIV and AIDS response, or the level of mobilisation of civil society organisations, including CBOs in support of populations at higher risk of HIV.

Firstly, to ensure representative analysis across the spectrum of organisations, the case studies cover all four populations with the overall highest HIV prevalence rates registered globally or at highest risk of HIV transmission and also highly vulnerable to stigma and discrimination and human rights violations: transgender women, people who use drugs, men who have sex with men and people from the Lesbian, Gay, Bisexual, Transgender and Intersex (LGBTI) population, and people living with HIV. Secondly, the thesis covers a wide geographic context, with analysis of a variety of contexts of high and low HIV prevalence and of concentrated and generalised epidemics (affecting mostly specific minority populations or affecting the general population respectively). The countries in the case studies belong to three different continents (Honduras and El Salvador in the Americas, Uganda in Africa and Ukraine in Europe) and range from high and generalised HIV prevalence in Uganda, to low and concentrated in El Salvador.

Finally, all CBOs studied in this thesis are categorised as grass-roots organisations or structures, regardless of their degree of development, representing a specific group of people who share one or more characteristics defining them as belonging to a particular population. These organisations are managed by and composed of members of the population they represent and aim to provide services to or advocate on behalf of their population. However,

the degree of development and cohesion of each CBO varies greatly, from highly organised entities often considered as NGOs due to solid governance and management structures such in the case of El Salvador and Ukraine, to highly unstructured organisations in Honduras.

The case studies are ordered from a lower to a higher degree of influence of the CBOs studied on the diffusion of international norms in their respective countries to help analyse the factors that facilitate such role and the strategies CBOs put in place to influence their states. The first case study focuses on the role of CBOs of transgender women in the HIV response in Honduras, and represents the least level of influence on the diffusion of human rights-based HIV norms of all the cases presented in this thesis. The chapter finds that despite a low level of organisational structure and resources, transgender organisations in Honduras play a critical role in the ownership of international human rights norms among the population they represent. This assimilation of human rights norms is essential in the generation by these CBOs of a limited local practice based on the provision of peer-to-peer HIV prevention services among transgender sex workers and some human rights services, such as para-legal counselling to transgender victims of violence. It also prompts the CBOs themselves to want to advocate for changes in state policies. However, these CBOs are unable to influence national practice contradicting international human rights norms that state representatives have committed to adopting in a context of impunity around widespread transphobia (hatred, violence, discrimination and stigma), both within the wider community and in state facilities such as detention centres, and health care facilities.

The second case study represents a step up in the role and influence of CBOs in the diffusion of human rights-based HIV norms. The chapter analyses CBOs of people who use drugs in Ukraine. As in the previous case of Honduras, these CBOs play an important role in generating local practice through the implementation of the HIV response among people who use drugs. However, in this case CBOs do manage to obtain ample recognition of their role by donors to the response, which in turn are big proponents of harm reduction programmes, based on human rights norms. This international recognition and appropriation by members has allowed CBOs to reinforce their structures as implementers and advocates and to influence parts of government by opening a limited space for human rights norms to integrate state health policies through the harm reduction programmes these organisations provide with the recognition of the Ministry of Health. However, the case study shows that CBOs have not been able to influence government policies on drugs, which are heavily dominated by security considerations. The case study provides evidence of the interference of several norm diffusion

processes as regards to drug use, with key state actors privileging international security norms over international human rights norms in this regard, and showing marked contradictions in the positioning of the state as a whole towards these processes.

The third empirical chapter presents the study of CBOs of LGBTI people in Uganda. Similarly to the previous case of Ukraine, state actors such as government officials, politicians or the judiciary navigate between a strong rejection of international human rights norms as regards the discrimination of people on the basis of sexual orientation and gender identity, and the need to appropriate human rights-based HIV norms to gain support from donors to curb a fast-growing HIV epidemic. However, unlike CBOs in Ukraine, CBOs of LGBTI people in Uganda have, until recently, had limited participation in the HIV response. These organisations have based their work on the assimilation of international human rights norms among members attracting a large international constituency of both state actors and international NGOs and human rights institutions to their support. LGBTI organisations in Uganda have also influenced key external actors in HIV/AIDS governance to put pressure on the Ugandan government, heavily dependent on international funding to sustain its HIV response, to uphold the rights of LGBTI people, critically affected by HIV. As a result, openly homophobic state representatives have overturned their contestation of international human rights norms banning discrimination on the basis of sexual orientation and gender identity. At least for now, the introduction of proposed legislation further criminalising homosexuality has been put on hold.

The fourth and final case study, presents the maximum degree of influence of the CBOs studied in the diffusion of human rights-based HIV norms. The chapter studies the role of CBOs of people living with HIV in El Salvador. This population is particularly representative of populations at higher risk of HIV in the country, not only due to the high risk of HIV transmission and the high level of stigma and discrimination associated with HIV status, but because the HIV epidemic in EL Salvador is largely concentrated among men who have sex with men, in itself another population at higher risk of HIV and highly vulnerable to human rights violations. As the case study describes, CBOs of people living with HIV decided to focus on campaigning for the right to access HIV services rather than demanding human rights based on sexual orientation or gender identity. The chapter describes how members of these CBOs embraced international human rights norms around the right to health, being able to influence both local and international actors, mostly human rights proponents, using existing regional human rights instruments, such as the Inter-American Commission of Human Rights (IACHR), and finally influencing the government which made a complete U-turn in their human rights

and HIV policies, becoming a champion of human rights-based HIV norms. CBOs in El Salvador were able to influence a myriad of local actors, including parts of the media and the medical profession which in turn could influence the government and other key state actors; they also used the regional human rights governance system in full through strategic litigation and leveraged it to influence the state's overall position regarding international HIV norms.

It is important to note that all case studies in this thesis champion international human rights-based HIV norms for the protection of the populations they represent. The empirical analysis does not study strategies of community-based groups and other non-state actors with opposing normative agendas (for example, anti-drug use groups). However, the purpose of this thesis is to analyse the role of CBOs of populations at higher risk of HIV in the diffusion of norms and the influence they may have among key actors in norm diffusion processes without comparing such influence with the impact and strategies of other state or non-state actors. The evidence generated in the thesis as to this role does not exclude or deny the role of other organisations or institutions with opposing strategies and the influence they may also have in the diffusion of international norms. The existence of opposing strategies from non-state actors other than the CBOs analysed in the case studies is acknowledged throughout the thesis and particularly evident in the chapter on Uganda, which refers to the influence of anti-homosexuality organisations and institutions on the positions of key state representatives.

The research methodology was based on field observation and 132 semi-structured interviews with members and leaders of the CBOs mentioned above and other non-governmental organisations (NGOs), representatives of intergovernmental agencies, government officials, members of the judiciary, law enforcement agencies, legislative, social and religious leaders, media representatives, academics, and other key actors. Besides the interviews, in all case studies there were two other main sources of information. Firstly, epidemiological data, including country reporting, publications by the United Nations Joint Programme on HIV/AIDS (UNAIDS), and other relevant documents provided the context of the response to HIV. Phone interviews with representatives of the International HIV/AIDS Alliance (IHAA) in country furthered the context analysis and helped complete mapping of the main organisations and institutions involved in the response, including NGOs and CBOs involved in either the implementation of the National Strategic Plan on HIV and AIDS, the Country Coordinating Mechanism of the Global Fund to Fight AIDS, Tuberculosis and Malaria (Global Fund), or both. Secondly, all case studies refer not only to the academic and policy debates discussed in the theoretical framework and literature review section of this thesis, but also to

other literature specifically focused on the country and population in question of particular relevance to the main elements of the research question of this thesis around the role of CBOs in the HIV response in the country and analysis of state policies as regards to the response and/or the human rights of the populations studied (Beissel-Durrant, 2004).

The field research was carried out through the support of national HIV NGOs in Honduras (Redlactrans), Ukraine (international HIV/AIDS Alliance in Ukraine), Uganda (Community Health Alliance Uganda), and El Salvador (Atlatl *Vivo Positivo*), all members of IHAA, which funded the field research. In the case of El Salvador, the organisation supporting the research was also studied in the case study. Individual interviews with CBO members were conducted in IHAA offices in these countries or in premises of CBOs supported by IHAA. Interviews with people living with HIV or populations at higher risk of HIV (such as MSM, people who inject drugs, or transgender sex workers) were only carried out among people already benefiting from programmes supported by IHAA supported programmes of HIV treatment, prevention or care and support.

The content of the interviews was adapted from country to country and according to the interlocutor. Questions in the interviews carried out among general members of the populations where each case study focused revolved around general perceptions of informants about the impact of HIV in the communities they live in, how the community responds to it, how people living with HIV are affected by HIV, which human rights are most associated with HIV, and the role of the CBO they belong to and state in providing for people affected or infected by HIV. The main object of these interviews was to try to understand the degree of understanding and appropriation of international norms by members of CBOs and to what degree such norms were present in the descriptions these informants made of the work of their CBOs. Answers to this particular question were contrasted with interviews with CBO leaders. As regards to CBO leaders, questions were more focused on the objectives and strategies these organisations pursue and what place HIV and human rights play in their services and interventions and in their advocacy strategies. These questions helped ascertain whether the CBOs studied can generate their own local practice based on their embracing of human rights-based HIV norms.

Interviews with state representatives, NGOs, representatives of global HIV/AIDS governance institutions and other observers focused more around country policies and practices as regards to HIV and human rights for affected populations and their analysis of the

influence of CBOs in such policies. Together with the analysis of policies, epidemiological and policy reporting, and norm diffusion, HIV and human rights literature, the interviews helped answer the central research question of the thesis: what role can CBOs of people at higher risk of HIV play in the diffusion of human rights-based HIV norms domestically? Particularly enquiring about their own action in fostering the appropriation of such norms among the populations they represent and in their provision of HIV/AIDS interventions among these populations, and about their possible influence on the appropriation and implementation (compliance with and enforcement) by the governments and other key state actors where these organisations operate (see examples of interview questionnaires in Appendix 1).

The most common format of interviewing was semi-structured, which facilitated interaction with a diversity of people affected by or working on HIV at the community level regardless of their educational background. This format of data collection is flexible enough to adapt to very different cultural and educational backgrounds and to explore what HIV means in human rights terms for various actors while allowing interlocutors to express themselves in their own words (Beissel-Durrant, 2004). The field research adhered to confidentiality, prior informed consent, and security protocols of IHAA, which funded the visits, and the University of Sussex. An important factor to be taken into account is that all field visits took place along with field work for the IHAA and therefore there could be risk of contamination of the interviews with informant being confused about the nature of the interview. Particular emphasis was given to provide full explanation verbally about the objectives of the interviews and the use of the information provided by the informants verbally and in writing (Coomans et al., 2009).

Given the sensitive nature of some of the questions asked, in particular about human rights context and HIV status of informants, no focus group discussions were organised. All interviews were only conducted in private and after full informed and written consent was given by each informant (see Appendix 2). The answers were not be attributed directly to the informant's own name and, with the exception of prominent activists or public figures who consented to be named, they were documented through a secure coded system to avoid providing details that could lead to the person being identified. For local languages, personnel from the IHAA familiar with the sources being interviewed and the local context were briefed to serve as translators. Interviews were only carried out once informants had given their informed consent and signed an authorisation form. Interviews were conducted in English or Spanish as appropriate or in local languages through translators as described above. Interviews

were recorded and transcribed by the interviewer, lodged safely and filed under reference codes and not real names.

In the concluding chapter, the thesis contrasts the findings summarised of the field research with some of the main assumptions made and gaps encountered in norm diffusion and related IR and development literature. The chapter summarises the ways in which CBOs of people at higher risk of HIV can influence the diffusion of international norms and their introduction into domestic practice. It also outlines other major contributions of the thesis to norm diffusion theory. The chapter also describes the main limitations of this research, the implications of the findings for IR literature and concludes suggesting key avenues for future research in this area.

2. THEORETICAL FRAMEWORK: FROM INTERNATIONAL NORMS TO DOMESTIC PRACTICE

Introduction

This chapter presents the main academic debates around the generation and diffusion of international norms, focusing mostly on norm diffusion literature but drawing also from other areas of IR theory and related disciplines, notably social anthropology, human rights and public health. The chapter identifies the main points of agreement and debate around the study of international norms. It goes on to describe how the theory around this very point has been applied by scholars within and outside IR to global health, particularly those studying the global governance and response to HIV, pinpointing the contribution that authors in this area have made to better understanding how international norms travel and influence policies, but also highlighting gaps in literature this thesis fills in order to help further such understanding of international norms.

In particular, this chapter shows contradictions and gaps in IR literature as to the full extent of the role of non-state actors in the diffusion of international norms at the domestic level, which the thesis' empirical analysis demonstrates. Scholars studying norm diffusion theory focus on the behaviour of states in relation to international norms reflected in their national practice as the only appropriators and implementers of international norms. Global health and vernacularisation literature are the other two main theoretical pillars this thesis used to complement its analysis of norm diffusion theory, as they do attribute a significant role to non-state actors such as social movements, NGOs or CBOs in the assimilation and translation of such norms into the local context and their implementation on the ground, particularly in the response to HIV/AIDS epidemics. These areas of literature however do not extend their analysis to the impact that such roles by non-state actors could have on the processes whereby international norms are diffused, a connection this thesis establishes.

Norm diffusion literature can be classified into three broad areas, which build from each other to enrich the analysis of international norms. First, the focus on international norms themselves, both in nature (static or dynamic) and in the way they travel from when they are generated to their adoption by states. Second, the focus on the relevant actors in the diffusion of such norms, from looking only at states as they are the ones adopting (taking) international norms, to analysing an array of state and non-state proponents or opponents of a

given norm. And finally, a level of analysis which looks at international versus national, from the focus on the generation and appropriation of norms by states at the international level, to the analysis of the interface between international and local level. In relation to these debates, the chapter argues that there are several areas in the theoretical framework of norm diffusion that need further exploration if we are to fully understand how norms evolve to the end point of being complied with and enforced at the local level: 1) Are states the only end point of the practice of international norms? Can actors, other than state actors generate their own practice based on these norms? 2) What influences state actors' behaviour at the level of norm implementation? 3) What role do local actors play in influencing such behaviour? 4) Which factors intervene to make governments and other state actors re-position themselves in relation to a particular international norm? 5) How does the behaviour of state actors in relation to a norm diffusion process affect their behaviour regarding other related norm diffusion processes?

The chapter goes on to explore in depth current literature on human rights and health (with an emphasis on HIV and AIDS) analysing how it has contributed to the wider debate on norm diffusion. Global health literature largely agrees that the HIV response is significantly regulated by international norms and that human rights principles have been profusely integrated in global HIV/AIDS governance (Piot et al., 2009; Wolff, 2012; Brown, 2014). Literature also acknowledges the significant role that CBOs of those affected by HIV play in the implementation of global health norms in responding to HIV on the ground. Herein exists an important gap in norm diffusion literature applied to global health. If according to authors, CBOs of people at higher risk of HIV are indeed so critical to the success of internationally-generated norms to respond to HIV, what role do CBOs of people at higher risk of HIV play in the diffusion of human rights-based HIV norms domestically?

The study of the generation and diffusion of international norms

International norms, understood as standards of appropriate behaviours (Finnemore and Sikkink, 1998), are at the core of the study of IR theory as their role is to govern or at least influence the behaviour of states both in their relations among themselves and in their policies. They are an "integral part of the flow of politics aimed at meeting instrumental needs and addressing normative concerns" (Stoeva, 2010:1). The study of how international norms are created and diffused into the national practice of states originates in constructivist approaches to norms as structures that regulate the relationship between states and non-state international

actors in a dynamic of norm promotion and creation, socialisation among states, and eventual adoption of international norms by states (Checkel, 1998; Wendt, 1999; Joachim, 2003; Reus-Smit, 2009).

Constructivists usually approach norms from a perspective of moral cosmopolitanism, whereby “good international norms prevail over bad local beliefs and practices” (Acharya, 2004:239) as they carry a high moral standard of appropriateness (March and Olsen, 1989). According to Wendt, the international order relies on shared ideas and beliefs as to what constitutes appropriate behaviour (Wendt, 1999). Two main considerations around international norms are worth noting in this respect. Firstly, the important role that perceived moral values play in foreign policies of states when they interact with other states (Lumsdaine, 1993). Secondly, universal values embedded in international norms compel states to sooner or later abide by these norms as illustrated for example in the eventual end of slavery or apartheid (Nadelmann, 1990; Finnemore and Sikkink, 1998). The direct conclusion about the moral case around the emergence of international norms made by constructivists is that being morally ‘superior’ to local norms or beliefs, international norms travel virtually untouched as static elements up until they are appropriated (accepted and adopted) by states.

Constructivists differentiate international norms between those that are enforceable to compel state behaviour, referred to as regulative, and those which create new interests or categories of action, called constitutive (Ruggie, 1998). However, given the moral charge and universal nature attributed to international norms by constructivists, these norms tend to be regulative. International norms can be divided between legal rules and non-legal norms, or between security and non-security norms, with the former referring to norms affecting national security, for instance arms control. Non-security norms include broader issues such as human rights and global health which according to Stoeva are much less conducive to cooperative state action leading to consistent state compliance. Non-security norms comprise technical knowledge and normative beliefs, both components are present and essential to understanding their nature as products of both social rules and laws of science (Stoeva, 2010).

However universal international norms might be, most authors recognise that the study of the diffusion of norms is complex as it encapsulates a wide variety of considerations among states as to what constitutes generally-recognised principles, the fact that norms often fail to attain their intended goals as they travel and are diffused, and the complexities of a normative space where norms must compete with other norms (Meyer et al., 1997; Finnemore

and Sikkink, 1998). This thesis focuses part of its analysis precisely on this often ignored point in literature about competition between international norms over the same normative issue, but belonging to different international governance systems, for instance, human rights norms versus national security norms, each with their own sets of shared values and beliefs.

International norms: static or evolving in dynamic processes?

How norms actually travel is arguably the central object of study and debate in norm diffusion literature and various theories have been developed to analyse how these norms change other elements of IR and policy. The first of such theories, developed by Finnemore and Sikkink, contrasts with the static consideration of norms in constructivism. According to these authors, norms change and evolve as they travel through life cycles of emergence, diffusion and, at the very end of the cycle, internalisation by states, when the norm is widely accepted, complied with and implemented by state structures to the point of being taken for granted not being any longer a “matter for public debate” (Finnemore and Sikkink, 1998:895). After emerging, international norms are adopted by a growing number of actors through a process of persuasion, until there is a critical mass of actors who create a tipping point at which it can be said that the norm is so widespread that it is diffused. Norms travel in cascades, in a process of imitation with states jumping on the bandwagon of other states that adopt and advocate for wider endorsement, until the international community reaches wide acceptance. With their life cycle model, Finnemore and Sikkink overcome the difficulty constructivists have in explaining change. However, they still describe a unidirectional process whereby norms are generated internationally and adopted nationally, presenting norm diffusion as processes where norms are dynamic rather than static structures but which do not travel back from local to global (Wiener, 2004; Sandholtz, 2008; Brown, 2014).

Much like in the case of the life cycle model, the spiral model focuses on the impact of norms on the behaviour of states at the moment socialisation of international norms among these states. The model presents five phases in socialisation, including domestic repression, state denial, tactical concessions, prescriptive status and finally, rule-consistent behaviour (Risse and Sikkink, 1999; Schmitz, 1999). Although the spiral model still lacks acknowledgement of the evolutionary nature of norms as they are diffused (Krook and True, 2010) and it is still fundamentally unidirectional (norms travel directly from international to domestic via state appropriation), it acknowledges a degree of negotiation at the moment of socialisation by states which brings an element of back and forth of the norm up until it is appropriated.

Krook and True advance on the dynamic nature of norm diffusion introducing a discursive approach of particular interest in the context of this thesis as to the influence of non-state actors in the diffusion of international norms. To overcome the static nature of constructivist approaches to international norms, Krook and True analyse the evolution of norms as to their internal definition (internal dynamism), what they really mean for the key actors involved; as well as their interaction with the normative environment where other norms are also evolving (external dynamism). This dynamism fosters the creation of new norms, but it also facilitates the redefinition of such norms and their adaptation to the local context altering their initial formulation and the way they are implemented by norm takers in what they describe as processes of norm diffusion (Krook and True, 2010). This thesis uses Krook and True's approach to describe HIV norms, human rights norms and other related norms, such as security, as evolving in distinct norm diffusion processes which may belong to diverse international governance systems, each codified with distinguishable sets of norms and standards, and with specific and recognisable international governance structures and actors. The work of Krook and True is also relevant for the thesis as, unlike most other authors in norm diffusion, they place the evolution of international norms in the context of their relationship with other international norms, which this thesis analyses in detail.

Acharya adds an additional stage to the norm cycle: localisation. He does not take for granted that states just adopt norms that have been widely appropriated by other states and rejects constructivist ideas that international norms have a higher moral ground than local beliefs as he sees many of these beliefs as legitimate norms in the context where they exist. Acharya believes that at local level, states reconstruct international norms to fit pre-existing local norms in a process he calls localisation. This process builds from the congruence building model whereby "states build congruence between transnational norms...and local beliefs and practices....In this process, foreign norms, which may not initially cohere with the latter, are incorporated into local norms" (Acharya, 2004:241). This model highlights that norm diffusion is indeed an unpredictable process where states negotiate the congruence or incongruence between international norms and domestic conditions in a process of congruence building (Stevenson, 2013), underpinning the consideration that international norms are actually never transcribed straightforwardly to the local level and that the role of local leadership, still understood as key state actors, is key as to how this translation takes place (Brown, 2014).

Acharya's model contributes to the norm diffusion process by adding a sub-process of reinterpretation and re-representation of international norms that takes place by state-actors

at the local level and which can result not only in a substantial transformation of international norms at the local level but also with norms being returned for renegotiation at the global level creating an iterative process of re-diffusion. Acharya also alludes to the notion of norm displacement, whereby norm diffusion can indeed fail if an international norm tries to overturn an existing local norm which has a strong moral and legitimate appeal embedded in strong local institutions (Acharya, 2004). Unlike vernacularisation theory (described below in this chapter) localisation theory still focuses on state-centred processes of norm diffusion and only considers states as actors of localisation. Furthermore, like the other models described in this section, the localisation model does not analyse which factors may cause states to re-consider their own decisions to reject, appropriate or localise a particular international norms. Localisation carried out by non-state actors and the re-consideration of states' positions regarding international norms are important points of analysis in this thesis.

Which actors matter in the diffusion of international norms?

Throughout the study of international norms, including among constructivists, there is ample recognition of the existence of multiple actors, other than the states, and their influence in the emergence and diffusion of norms (Stoeva, 2010). However, the central actors in the context of norm diffusion are invariably states, often referred to as norm takers, as they have the ultimate role to commit all actors in their jurisdiction to the compliance with international norms and are responsible for the incorporation of such international norms into the national practice undertaken by state actors and structures through compliance with and enforcement of the norms the state has appropriated (Checkel, 1998; Cortell and Davis, 2000; Acharya, 2004; Björkdahl, 2005; Domínguez, 2010). This overwhelming focus on national practice placing the state as the main repository of the norm diffusion process gives little space for the analysis of other possible practice or practices. Is there just national practice? Can there be local practice implementing international norms carried out by non-state actors even when this practice is not aligned to the policies of state actors? In other parts of IR theory this debate is wide open, at least in relation to the obligation to protect and provide for human rights. For example, for Rawls and Beitz, human rights practice is solely carried out by states as they are legally bound by the international human rights standards on which the international human rights system is based (Rawls, 1999; Beitz, 2009). For Karp, however, there is "the meaningful possibility of assigning and attributing duties to protect human rights to non-state actors in some political contexts" (Karp, 2013:972). In its empirical analysis, this thesis challenges the sole focus of

norm diffusion theory on national practice. It does not however explore what constitutes international practice or the obligation of non-state actors regarding international norms, but the generation of local practice by such actors, through the study of the role CBOs of people at higher risk of HIV in relation to international human rights-based HIV norms.

Outsider proponents (or external norm entrepreneurs) in norm diffusion theory are actors operating at the international level, such as international NGOs or think tanks, for instance, who commit to promoting the universality of a set of norms (Wiseberg, 1992; Lauren, 1998) and aim to advocate for and influence the generation or modification of such international norms (Clark, 2001; Tsutsui and Wotipka, 2004; Kravtsov, 2009; Greenhill, 2010). The extent of the study of the behaviour of these outsider proponents and the degree of agency attributed to them to influence international norms and their diffusion varies considerably from author to author. However, even those authors who focus more on non-state actors often circumscribe their analysis to actors at the international level, particularly the influence of TANS at the time where norms are generated and negotiated prior to being appropriated by states (Keck and Sikkink, 1998; Risse and Sikkink, 1999; Gränzer, 1999; Hertel, 2006).

Finnemore and Sikkink's life cycle model confers an important role to organisational platforms, comprised of both international NGOs and larger TANS as key promoters of international norms at the early stages of the emergence of a norm. These norm promoters, or norm entrepreneurs, often need to persuade states to endorse the norms they champion as the only way for norms to be socialised among states and eventually reach a critical mass of acceptance. Finnemore and Sikkink and other authors acknowledge a high degree of rationality among transnational norm entrepreneurs, who make highly sophisticated calculations in their strategy to persuade other actors to align with their own normative commitments (Nadelmann, 1990; Keck and Sikkink, 1998; Finnemore and Sikkink, 1998). The thesis produces evidence of this rationality among CBOs trying to influence norm diffusion processes at the domestic level.

Norm diffusion pays far less attention to internal proponents (or internal norm entrepreneurs) and opponents, who are relevant internal actors within the jurisdiction of a state, which could include local elites, NGOs or other active civil society groups playing a role in norm diffusion processes by advocating to the state and/or mobilising public opinion and political support both nationally and internationally for an international norm to either be adopted, localised, or contested by the state (Nadelmann, 1990; Acharya, 2004; Kravtsov, 2009). This

thesis contributes to fill this gap in the study of internal non-state actors in norm diffusion by including CBOs in this category when referring to international HIV norms. This categorisation is consistent with the significant role that global health literature attributes to CBOs formed of people at higher risk of HIV in the responding to HIV among the populations their represent (Reza-Paul et al., 2008; Mburu et al., 2012; Harman, 2012).

The spiral model does indeed recognise the existence of local actors, including local activists. However, as in the case of the life cycle model, the spiral model gives little agency to local actors and circumscribes their role to their connection with transnational advocacy actors at the early stages of norm diffusion, at the moment of socialisation, without taking into account the role these actors play when the international norms are to be implemented at the local level (Risse and Sikkink, 1999), a key area of analysis in this thesis. The special consideration and analysis of non-state actors is also a key contribution to the boomerang effects model, which gives significant importance to the role of TANs in norm diffusion processes. Keck and Sikkink argue that, even when states choose to contest or reject a norm, other actors within the jurisdiction of these states can connect with international actors, including states and TANs advocating for a particular norm, to persuade or force the state in question to adopt the norm. This represents a strong recognition that TANs can influence the framing (contextualising emerging norms to the issues addressed by existing norms) and grafting (associating directly a new norm with a pre-existing norm in the same area) of norms by influencing negotiation taking place at the moment of socialisation of norms (Keck and Sikkink, 1998; Finnemore and Sikkink, 1998). Although this model seems particularly interesting in the context of the analysis of local actors central to this thesis, in reality, the role of these actors is again circumscribed to their connection within TANs, and they are given very little agency in themselves. Additionally, literature focuses on the role of TANs at the level of international socialisation, prior to the appropriation or contestation of norms by states, with little reference to the implementation phase at the local level, on which this thesis places its emphasis.

In order to gain a better and more nuanced understanding of the relationship between internal non-state actors and international norms, social anthropology, in particular vernacularisation theory, arguably offers a better base of analysis than norm diffusion. Vernacularisation can be defined as the “process of appropriation and local adoption of globally generated ideas and strategies” (Levitt and Merry, 2009:441) and centres its analysis on NGOs, social movements, cosmopolitan elites, and other local actors (Orr, 2012). This area of literature is particularly relevant to the theoretical framework of this thesis as it offers an analysis of how

organisations such as CBOs appropriate international norms, and the factors that contribute to this. The conditions as to whether and how this appropriation takes place depend on where these organisations are located in the social and power hierarchy; which channels of technology are used by these organisations; what kind of ideas are being packaged by these organisations; and the social and political context where all this happens (Snow et al., 1986; Tarrow, 2005; Levitt and Merry, 2009).

Merry offers what can be interpreted as a critique of constructivism when referring to the appropriation of human rights principles. According to this author, these notions are influenced by local and cultural constructs of the role and status of individuals, communities and the state itself, and therefore appropriation does not happen straightforwardly and varies from setting to setting. However, this analysis is consistent with the moral cosmopolitanism of international norms defended by constructivism, as she claims that the vulnerable people represented by these local organisations see in international human rights norms hope against their marginalisation (Merry, 2006a). This point is widely explored in this thesis, as it is central to the analysis of the appropriation of international human rights norms by CBOs of populations at higher risk by HIV.

According to Levitt and Merry, local non-governmental organisations and social movements serve as vernacularisers as they frame global principles adapting them to existing local principles abandoning direct references to international language which could lead to a rejection by local elites (Levitt and Merry, 2009). For Merry, “intermediaries such as community leaders, nongovernmental organizations participants, and social movement activists play a critical role in translating ideas from the global arena down and from the local arenas up” (Merry, 2006b:38). Without mentioning norm diffusion explicitly, these authors are describing a process of localisation of international norms not just by states, but also by local norm entrepreneurs such as social movements or community leaders. However, vernacularisation offers no direct connection with norm diffusion theory as to how the local organisations and actors analysed in vernacularisation may or may not influence the actual diffusion of the international norms they have appropriated. This is a central point of empirical analysis in this thesis.

The international versus the local level of norm diffusion

All theoretical models of norm diffusion described so far and the vast majority of the analysis of norms diffusion focus mostly on the process that takes place at the international level, when norms are proposed and socialised through a negotiation that leads to the state appropriation

and adoption of an international norm and its eventual incorporation into national practice (Risse and Sikkink, 1999; Davis, 2000; Stoeva, 2010; Towns, 2012). The connection between international and local is also present in most analyses of norm diffusion, although largely circumscribed to the role of the state. The life cycle model acknowledges this global-local connection by referring to domestic norm entrepreneurs who might use international norms to strengthen their position in their domestic advocacy. An important point in this relationship, which this thesis contests, is that domestic influences mostly take place at the beginning of the life cycle and tend to diminish once a norm has become institutionalised internationally (Finemore and Sikkink, 1998). The case studies of the thesis demonstrate that such influences may actually increase as the norm is diffused and continue even after the norm has been contested, localised or appropriated by the state.

Acharya's model of localisation described earlier illustrates like no other the work of norm diffusion literature focusing on the domestic processes which take place when principles of international norms meet with the realities of domestic conditions (Acharya, 2004; Stevenson, 2013; Brown, 2014), when states adapt an international norm that they have appropriated before domesticating it (Checkel, 1998; Gurowitz, 1999; Farrell, 2001). Acharya gives local agents, beyond state structures, a more active role in norm diffusion processes, as they contribute to the reconstruction of international norms made by state in their localisation, a process which does not constitute either blank appropriation or total rejection of norms, but which according to Acharya settles most cases of normative contestation (Acharya, 2004). Acharya defends the agency of states, which adapt and modify norms according to local priorities and structures through the framing and grafting of international norms to the local context (Acharya, 2004).

For Brown, this localisation is multidirectional, and allows for modification of norms along the way as national leadership (still largely circumscribed to state actors at the higher level of political hierarchy) play a role in appropriating or otherwise, contesting, modifying, adapting or disregarding norms. According to Brown, norm diffusion models pay too little attention to the intersubjective *glocalisation* that occurs in the interface between the global and the local (Brown, 2014:881). Brown builds his analysis of norm diffusion on the normative congruence building model to help understand the effects of diffusion on national policy and critiques the general assumption in norm diffusion literature that international norms have a direct positive influence in national practice. Brown agrees with Acharya that state actors are unlikely to appropriate international norms straightforwardly without the influence of domes-

tic social foundations and practices, in particular, national leadership (Brown, 2014). Brown centres his analysis of norm diffusion within global health governance, and more particularly on HIV and AIDS, making his work especially relevant to this thesis and extensively referred to later on.

Analysis of the domestic impact of international norms on the salience of a particular norm domestically is also relatively marginal in norm diffusion literature. Such salience can be determined through analysing how the state reforms structures and institutions, modifies its political discourse and policies and enacts laws to implement the international norm (Keohane, 1989; Koh, 1997). Cortell and Davis identify five main factors that contribute to the domestic salience of international norms: cultural match between the new norm and pre-existing domestic understandings among internal actors; changes in political rhetoric contributing to generating collective understanding of the new norm, particularly effective in autocratic regimes; domestic interest, the perception among internal actors of the new norm supporting their own interests; domestic institutions, in particular when national laws and policies reflect the new norm; and socialising forces, as the relationship between the effect of international socialisation of the state and the state's domestic political context (Cortell and Davis, 2000).

Davies et al., study state compliance in relation to norms of the Infectious Disease Control Regime, which underpins the securitisation and emergence of health as a major foreign policy issue which has persuaded states to adopt a robust IHR framework, arguing however that "the acceptance of new behavioural expectations [about the implementation of IHR by states] does not automatically result in those expectations being fulfilled" with some states deciding not to comply with some aspects of the regime showing their own practices in relation to global norms (Davies et al., 2015:3). The thesis contributes particularly to the analysis of this late stage of norm implementation aiming at contributing to the central object of the study of international norms in IR theory as to whether or not an international norm is integrated into national practice.

Norm diffusion in human rights and global health literature

Existing norm diffusion literature offers ample analysis on the two areas which frame the theoretical and empirical analysis of this thesis: international human rights and global health norms. Indeed, the vast majority of the theoretical study of norm diffusion described above identified the diffusion of international human rights norms as the central focus of analysis.

Considering that the international human rights governance system has developed considerably over the past decades and the relevance human rights norms and principles have to billions of people across the globe, there is little wonder that authors have profusely used norm diffusion theory to explain how international human rights standards shape human rights policies on the ground and which mechanisms of appropriation and adaptation take place in the process through the study of international governance institutions, civil society, citizens, and national governments (Keck and Sikkink, 1998; Greenhill, 2010).

International human rights norms were already a ‘perfect fit’ in the early analyses of the norm diffusion framework. Indeed, few international norms represent more clearly the constructivist notion of global norms having a higher moral ground than perceived “bad” local beliefs and practices (Acharya, 2004:349). Risse and Sikkink thus believe that international human rights norms provide an excellent opportunity to explore the theoretical study of the diffusion of international norms and principled ideas for two main reasons. Firstly, because “international human rights norms challenge state rule over society and national sovereignty”, and secondly because “human rights norms are well institutionalised in international regimes and organisations and are contested and compete with other principled ideas” (Risse and Sikkink, 1999: 4).

Stoeva analyses the creation and diffusion of an international norm banning the use of physical and psychological torture, which resulted in entry into force of the UN Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (CAT) in 1984 and its Optional Protocol in 2002. This is another example of how the universal nature of human rights principles facilitated the cooperation among various international non-state actors to create a new behavioural norm (Stoeva, 2010). Krook and True chose the global promotion of gender equality as an illustration of the strong contestation that many human rights concepts, principles and norms carry. This high degree of contestation makes the positioning of key actors in the socialisation of human rights norms, in this case the UN Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW), particularly marked and prone for analysis of norm diffusion processes, even when international human rights norms do not lend themselves particularly well to the study of the role of non-state actors in their diffusion as they largely regulate the relationship between the state and its citizens (Krook and True, 2010).

This section focuses on the analysis of global health norms as they are another major

contributor to norm diffusion theory and a complement to the human rights-based analysis of norm diffusion. Within global health, the thesis focuses on the global response to HIV and AIDS, a generator of international norms which, as this chapter describes, are often closely related to international human rights norms (Piot et al., 2009). The analysis of the HIV-related literature shows that the global response to HIV has created its own global governance, with a distinct system of structures, actors and processes where international HIV norms, including human rights-based HIV norms, are diffused. This governance is demonstrated in the wide appropriation by governments of a number of political declarations and guidelines linking human rights and HIV and the existence of global HIV/AIDS governance structures such as UNAIDS and the Global Fund (Youde, 2012).

However, there is a marked disconnect between the little attention that authors studying the roles of key actors in the diffusion of international norms (including human rights and health norms) give to local agents in general as their main objective is to focus on the behaviour of states from the generation of these norms to their incorporation into the national practice of these states on one hand; and the essential role and thorough analysis that other parts of literature focusing on the HIV response give to CBOs of people affected by HIV (Reza-Paul et al., 2008; Campbell and Cornish, 2010; Mburu et al., 2012). This disconnect in literature justifies the focus of this thesis on CBOs of people affected by HIV. Given the critical role authors give to these CBOs as representatives of affected populations in the wider HIV response, these organisations indeed emerge as key in the study of the diffusion and implementation at the local level of human rights-based HIV norms, which poses questions to norm diffusion literature as to whether it should consider that these actors might be generating their own practice along with the national practice generated by state actors.

The study of the diffusion of global health norms and the case of HIV and AIDS

There is little dispute in IR literature that global health is an area where international norms have found fertile ground to diffuse as processes of a global governance defined as the “use of formal and informal institutions, rules and processes by states, intergovernmental organisations, and non-state actors to deal with the challenges to health that require cross-border collective action to address effectively” (Fidler, 2010:3). Global health governance can thus be defined as “trans-border agreements or initiatives between states and/or non-state actors to the control of public health and infectious disease and the protection of people from health risks or threats. It is a fluid term that encompasses an ever-changing pattern of actors –both

public and private, approaches, and priorities for both who are in the position to govern and those who are susceptible to poor health” (Harman, 2012:2).

Global health governance has grown considerably in the past few decades to cover an ever larger areas of health including HIV and AIDS, tuberculosis, malaria, or severe acute respiratory syndrome (SARS), with a much more complex interaction and collaboration among actors globally than early attempts of global health governance which were purely circumscribed to collaboration among states which retained exclusive control over their own health policies (Dogson et al., 2002). Global health matters a great deal because it has truly universal reach impacting on the health outcomes of millions of people and communities and therefore it is in itself an area that attracts attention of scholars in IR and related disciplines (Zacher and Keefe, 2008; Harman, 2009; Youde, 2012; Wolff, 2012).

There are two major characteristics of health norms within global health of particular interest in the study of norm diffusion undertaken in this thesis. Firstly, global health norms often flow from international organisations of global health governance in form of global health initiatives. These initiatives may reflect a variety of approaches and considerations, including ethical, technical/medical and institutional (Brown, 2014) and even widely accepted understanding of what should be done in global health, which “under certain circumstances may prove much more significant in governing behaviour” than a treaty which is not honoured (McInnes et al., 2012: S86). This means that, unlike the diffusion of human rights norms, where the generation and socialisation of such norms are mostly dominated by states, in the area of global health governance, most norms emerge through the guidance and policies of multilateral agencies and organisations. These actors include, for example, the World Health Organisation (WHO), the World Bank, or, in the particular case of HIV, Tuberculosis and Malaria, the Global Fund, but also global civil society and charitable organisations (McInnes et al., 2012), and pharmaceutical companies, which are obvious key players in strategies to widen access to medicines, a “central goal in global health governance” (Roemer-Mahler, 2014:899). This presents a wider field in which to study the interrelation among the various actors involved in the generation of international norms and the influence they have in the diffusion of such norms that human rights, although authors in this area also tend to focus their analysis on the international level of norm emergence at the early stages of norm diffusion (Harman, 2009; Barnes and Brown, 2011; Chorev, 2012).

Secondly, global health norms are also often less regulative than other international norms, as they tend to be guidance on good practice rather than legally binding standards, giving more room for states to adapt them to fit into their local contexts. This means that any meaningful analysis of global health needs to involve the local level. This characteristic is significantly present in Brown's contribution to highlighting the role of local leadership in the adaptation of international norms before they are integrated into national practice. According to Brown, "although global policy plays an important guiding role health norms are never transcribed straightforwardly and a central element to successful health governance remains vested in the nation and the leadership role it exerts" (Brown, 2014:877). Global health norms also permit more intervention by international actors with strong epistemological legitimacy such as, for instance the WHO, than norms from other governance systems, for example, global security. These actors are particularly successful in generating and effecting change on global health norms (Kamradt-Scott, 2012).

More specifically within global health, HIV and AIDS governance has been fertile ground for the analysis both by authors who have approached the global response to HIV and AIDS from a norm diffusion point of view (Barnes and Brown, 2011; Kamradt-Scott, 2012; Brown, 2014) and those who have approached HIV from other areas of IR theory (Seckinelgin, 2005; Clapham, 2006; de Waal, 2006; Biehl, 2007; Forman, 2008; Pogge, 2008; Marks, 2009; Nguyen, 2010; Baral et al., 2012). The international response to the global HIV and AIDS pandemic is of great interest in norm diffusion theory as it has made a significant mark in the diffusion of global health norms creating its own norm global governance system defined by the ensemble of principles, policies, guidelines, and norms produced by global HIV/AIDS governance structures, including UN agencies such as UNAIDS, HIV donors, and HIV-related government structures. At the 2001, 2006 and 2011 UNGA Special Sessions on HIV/AIDS (UNGASS), UN member states made commitments and set goals to fight HIV/AIDS and achieve Universal Access to HIV prevention, treatment, care and support. The UNGASS process marked an unprecedented international response to the pandemic which led to the provision of ARV treatment to over 15 million people living with HIV world-wide (UNAIDS, 2015) and set out the international political framework which has facilitated the creation and socialisation of international HIV norms (Piot et al., 2001; Vieira, 2007; Zembe et al., 2010; Brown and Labonté, 2011).

The creation and diffusion of international human rights-based HIV norms

Most authors studying the HIV epidemic and the global response given to it agree that, from the moment it is established that the right to life is threatened by HIV and AIDS, the sheer scale of the international pandemic that has caused over 30 million deaths and infected over 33 million people to date means that HIV and AIDS has a wider impact on the human rights than any other health-related issue (Gostin and Lazzani, 1997; Fee and Parry, 2008). HIV and AIDS have devastating effects on individuals and communities and the social fabric of many states that go well beyond health concerns. Authors agree that human rights and HIV are markedly intertwined both in terms of the human rights implications of the pandemic and the vast reciprocal influence between global HIV/AIDS governance and the international human rights system of norms, actors and processes (Mann and Tarantola, 1996; Gruskin et al., 2005; Piot et al., 2009). This relationship between HIV and human rights is reinforced by growing evidence that without providing a human rights-based approach to HIV the pandemic will never be overcome (Schwartländer, et al., 2011; International Commission on HIV and the Law, 2012; Clayton et al., 2014).

This multiple relationship between HIV and human rights facilitates the creation and diffusion of human rights-based HIV norms within global HIV/AIDS governance. These norms constitute the integration of international human rights norms in the development of international HIV norms, based on three main pillars: 1) international human rights norms applicable to the context of HIV and AIDS and political commitments made by governments to uphold human rights in the HIV response and its articulation by global HIV/AIDS governance structures (see Appendix 3); 2) key principles of a HIV response based on rights (equality and non-discrimination, equal access and full participation of stakeholders, community at the centre of programmes, capacity building of right holders and duty bearers and accountability); 3) the application of a set specific interventions aimed to improve the human rights context of people at higher risk of HIV (Clayton et al., 2014). These interventions include legal reform programmes, sensitisation of law enforcement officers and human rights training of health care professionals, gender and stigma and discrimination programmes, human rights monitoring and legal services related to HIV (Global Fund, 2013; UNAIDS 2012b). For some authors, human rights-based HIV interventions such as the establishment of legal protections against discrimination based on HIV status are indeed the result of the global diffusion of health norms and not only due to the diffusion applications of international human rights norms (Wolff, 2012; Brown, 2014).

Literature offers ample evidence that a number of international HIV norms are indeed infused with human rights principles (Mann and Tarantola, 1996; Altman, 1999; Piot et al., 2009; Maru and Farmer, 2012). For these authors, the international and communicable nature of the HIV pandemic has facilitated the notion that health in this context is an international public good, which concerns not only countries affected, but also the rest of the international community, fostering a revitalised recognition of health in foreign policy. This interest by the international community is consistent with the principle of universality of human rights and may have contributed to human rights principles finding their way into global HIV/AIDS governance in a manner that had never occurred before for a health issue (Cohen and Amon, 2007; Kickbusch and Erk, 2009; Wolff, 2012).

Part of literature sees the relationship between HIV and human rights from the point of view of the impact of the human rights context of those populations at higher risk of HIV on the effectiveness of the response against HIV and AIDS as was advanced very early on by Mann, who warned that abuses perpetrated against marginalised groups increased their exposure to the virus (Mann, 1987). No other condition remotely attracts the level of stigma and discrimination that goes with HIV status. HIV and AIDS thrive among poor, marginal and vulnerable communities, and are fuelled by gender inequality (Barnett and Whiteside, 2002; Elbe, 2008). An area of thorough study in this area is the impact of punishing legislation on the HIV response, especially laws criminalising same sex relationships, drug use, intentional HIV transmission and non-disclosure, and sex work. Most authors conclude that these laws have a negative impact on the access to HIV services of criminalised populations and to treatment in the case of people living with HIV (Kirby, 2004, 2011; Baral et al., 2009; Csete and Cohen, 2010; Ahmed et al., 2011).

The stand taken by these authors contrasts with traditional public health approaches, more focused on containing disease for greater society's sake, even at the expense of some of the rights of those most affected, (Gostin and Mann, 1994; Gostin and Lazzani, 1997). This debate illustrates a reality that few authors have explored in detail but which is thoroughly studied in the empirical analysis of this thesis. Human rights approaches to HIV generate international human rights-based HIV norms which in fact compete with other norms from other approaches (biomedical, security, based on societal norms) aimed at regulating the same normative issues. This thesis contributes to fill this gap through its analysis of the strategies and the influence that some of the CBOs of people affected by HIV studied in the thesis have

over the diffusion of international HIV and of human rights norms in various norm diffusion processes.

Further evidence of this competition of approaches leading to opposing global health norms being applied to the HIV/AIDS epidemic comes from the analyses of the impact of HIV interventions on human rights contexts, mostly in terms of moral and ethical considerations of specific biomedical interventions (Gruskin, 2004; Jürgens, 2006; Kirby, 2007; Tarantola and Gruskin, 2007). For example, an area of spirited debate in literature is the impact that HIV responses might have on the human rights of those at higher risk of and affected by HIV in the context of HIV testing. This debate illustrates well how polarised HIV related literature is as to the nature of the norms that should prevail in HIV/AIDS governance: either pure public health considerations as to the greater health outcome for the wider population possible, or human rights principles protecting all individuals equally (Bayer and Edington, 2009). At one end of the debate, there are authors who advocate for wide-scale voluntary testing as a mean to effect behavioural changes in those at higher risk and to ensure prompt treatment for patients who test HIV positive (De Cock and Johnson, 1998; De Cock et al., 2002; Cameron, 2006; Granich et al., 2009). On the other hand, there are those who defend the exceptionalism of HIV in that routine voluntary testing in reality often takes place under coercive contexts which exacerbate the vulnerability of those at higher risk of HIV to stigma, discrimination and human rights violations, increasing exposure to partner violence in the case of women (Weiser et al., 2006). Authors associated with the UNAIDS Human Rights Reference Group are among the main critics of vast scaling up of HIV testing as being incompatible with the principle that testing in all settings requires consent based on informed decision making where the person can actively opt in having the test, not be given the option to opt out of it (Heywood, 2005; Jürgens, 2006; Kirby, 2007; Tarantola and Gruskin, 2007).²

CBOs and the generation and evolution of human rights-based HIV norms

Literature has thoroughly explored and acknowledged the role of CBOs of populations at higher risk in the programmatic response to HIV (Reza-Paul et al., 2008; Glynn et al., 2008; Sarkar, 2010; Seckinelgin, 2012; Restoy and Teltschik, 2014). This role is often referred to as the community mobilisation component of the HIV response, which can be defined as “a process

² The UNAIDS Reference Group on HIV is an independent body which advises UNAIDS on matters relating to HIV and human rights. The group has a multidisciplinary composition of experts. *Report of the meeting of UNAIDS Reference Group on HIV and Human Rights*, Seventh meeting, 12-14 February 2007 Geneva, Switzerland.

that capitalises on the strengths of communities to work collectively, in a locally-sensitive way, to bring about effective interventions, healthy communities and healthy public policy” (Cornish et al., 2012:4). Authors see community mobilisation as essential in the provision of services to the most marginalised and difficult to access populations through the institutional health systems (Campbell and Cornish, 2010; Gutierrez et al., 2010; Rodríguez-García et al., 2011; de Zoysa, 2012; Mburu et al., 2012). Whereas there is wide consensus in global health literature around the role of CBOs in the HIV response, much of the debate regarding global HIV norms in this respect has focused only on the agency of non-governmental organisations. Global health literature clearly refers to the influence of NGOs on the implementation of global HIV norms, and it often ignores CBOs as to whether these could also have a role in influencing HIV/AIDS governance, a gap this thesis contributes to fill.

A large portion of the analysis of civil society organisations and HIV undertaken within global health and wider IR literature has focused on the impact of the advocacy and campaigning undertaken by movements of people living with HIV from the late 1980s onwards, more at the global levels than locally. Successes of US-based organisations such as the AIDS Coalition to Unleash Power (ACT UP), and later in Brazil, South Africa (with Treatment Action Campaign - TAC), Uganda, (with The AIDS Support Organisation - TASO) and other countries are profusely analysed in literature (Robins, 2004, de Waal; 2006, Biehl, 2007). Smith and Siplon describe in detail the development and strategies of Health GAP, the first international AIDS-related campaign which in the late 1990s included activists from the global North and the global South (Smith and Siplon, 2006). In most of these cases, authors agree, the framing of the campaign for treatment around the right to access essential life-saving medicines proved a successful strategy in most countries (Marks, 2009; Nunn et al., 2012).

The richness of the work of Biehl and de Waal describing the role of organisations of people living with HIV in shaping the HIV response in Brazil and South Africa respectively is worthy of particular attention as they provide some valuable insights to this thesis as to the role of CBOs in the diffusion of HIV norms locally. Biehl describes the evolution of HIV activism in Brazil, which in 1996 became the first developing country to provide universalised access to ARVs. By the early 2000s, confrontation had already given way to close collaboration between civil society, including HIV organisations, and government. The HIV and AIDS sector became more of an industry with health and development professionals taking over from activists living with HIV and trying to adhere to the imperatives of international donors and policy makers (Seckinelgin, 2008). A negative side effect of this massive response in Brazil was the

biomedicalisation alluded to earlier in this chapter (which Biehl calls *pharmaceuticalisation*) of the response, almost exclusively centred on pharmaceutical distribution (Biehl, 2007). The revolutionary nature of HIV activists in Brazil contrasts with African HIV activism, which according to de Waal, has been more reformist than revolutionary (de Waal, 2006), with the significant exception of South Africa, where TAC activists took a more militant approach. TAC was able to create new forms of health citizenship from the grass-root level to the international one (Robins, 2004). In both Brazil and South Africa, court decisions based on the right to health, proved essential for the change in government policies (Marks, 2009; Nunn et al., 2012).

Social and medical anthropologists have long studied the impact on and strategies of survival of people affected by HIV and the societal dynamics of the epidemic especially in Southern and Eastern Africa, where HIV has had the most impact (Robins, 2004; Whyte et al., 2004; Fassin 2007; Marsland, 2012; Le Marcis, 2012). Biehl extends his analysis of the HIV response to the gaps of such response among the most marginalised populations in Brazil, and the strategies these populations took to counter such gaps. He describes how therapeutic policy based on ARV distribution in Brazil has not taken into account adherence and care and how negative that oversight is for the poorest and most marginalised risk groups. These groups have been left to their own devices to organise themselves around *casas de apoio* (support shelters) to adhere to treatment and save lives in what he describes as an economy of survival to “guarantee access to ongoing specialised medical care in a context of inequality and clientelism, not to mention housing and food and some form of legal accountability” (Biehl, 2007:320). Prince describes a similar system of moral economy of survival of people living with HIV in Kisumu, Kenya. She explores how these people have been able to express their needs around their new HIV identity, becoming visible to funding and services by NGOs working at the community level (Prince, 2012). From a norm diffusion point of view, although he does not refer to that part of IR literature, Biehl’s analysis gives great agency to CBOs of people living with HIV as appropriators and implementers of international HIV norms that have been contested by norm takers. The empirical analysis of this thesis on organisations of people living with HIV in El Salvador describes a similar kind of agency.

On the other side of the debate, some authors minimise the impact and agency of civil society, especially CBOs regarding HIV/AIDS governance, even at the time of activism for access to treatment. This is particularly evident in the case of authors analysing civil society in Africa, for whom decisions of community support based on HIV status or risk undermine local forms of

organisation and solidarity (Beckman and Bujra, 2010; Boesten, 2011) and patient activism is undermined by bureaucracy and donors' imperatives (Marsland, 2012). For Nguyen, international governance of HIV underpins the emergence of a therapeutic sovereignty, whereby it is those who administer HIV programmes in most affected countries (typically, international NGOs) who effectively decide who does or does not receive life-saving treatment, taking over a task that should correspond to the state. Nguyen refers to this situation as triage. In most countries in Sub-Saharan Africa, in the absence of government structures that guarantee and provide treatment, prevention, care and support for its citizens, it is NGOs that constitute the executive branch of a new Republic of Therapy (Nguyen, 2010).

Whereas Nguyen describes in detail how the therapeutic sovereignty is exercised and the consequences of this new governance on how HIV responses are constructed on the ground, how people living with HIV organise themselves, Seckinelgin focuses on the place of NGOs in the new global HIV/AIDS governance concluding that national NGOs and organisations, including those of people living with HIV, have very little agency to influence HIV policies even as implementers on the ground. This thesis interrogates extensively Seckinelgin's statement that "while NGOs have agency within the international policy context they gradually lose their local agency to influence people's long term behaviour. They become extensions of the international policy makers and for their policy implementation aims" (Seckinelgin, 2005:150). Harman reflects in a similar way as she acknowledges that national NGOs and small community groups, usually founded and led by people living with HIV, are indeed participants in HIV/AIDS governance, delivering community-responsive programmes, although she affirms that "such involvement in delivery at the community level has failed to translate to decision-making at the national and global level" (Harman, 2012:108).

Nguyen describes how a sort of therapeutic citizenship emerged among people living with HIV, especially in the early days of the epidemic, when coming out as a HIV positive person was both a statement of belonging to a new social group and a survival strategy to show up and be counted to access life-saving treatment. Unlike Seckinelgin, Nguyen attributes a degree of empowerment to donors' principles of the Greater Involvement of People living with HIV and AIDS (GIPA) for these people to be able influence HIV policies on the ground. Nguyen describes the way in which people living with HIV have organised themselves since the early days of the epidemic. For him, there was a clear interference by international HIV policy implementers forcing HIV positive people to come out, to give a face to the epidemic, in what he calls confessional technologies (Nguyen, 2010). However, Nguyen does attribute an

important solidarity value to the coming together of people living with HIV who were going public in what he calls a moral economy that developed among people living with HIV. The case study on the movement of people living with HIV in El Salvador in this thesis illustrates how this moral economy translated into an activism that was able to influence the diffusion of HIV norms by norm takers using the human rights system and its international norms as leverage.

Vernacularisation and the study of organisations of people at higher risk of HIV

Considering the importance given in part of literature to the role of CBOs of populations in the implementation of international HIV norms, and to the penetration of human rights norms within global HIV/AIDS governance, the lack of analysis on the role of CBOs in the diffusion and implementation of human rights-based HIV norms at the local level is noticeable and a main area of analysis in this thesis. The connections are however clear. On one hand, there is ample consensus as to the role CBOs play in the implementation of HIV norms, a role recognised in global HIV governance. On the other, the approaches to the HIV response that most CBOs of populations at higher risk of HIV undertake are clearly based in international human rights-based HIV norms according to the three criteria outlined by Clayton et al. Firstly, these CBOs service highly discriminated against and often criminalised populations, for example LGBTI people. This action is therefore deeply rooted in the human rights principle of non-discrimination. Secondly, often these CBOs provide such services because the government is unwilling to fulfil its own political commitments to do so (UNGA, 2011). Thirdly, most CBOs carry out human rights interventions and programmes as part of their HIV response, for example, sensitization of police officers on LGBTI rights, access to justice services to LGBTI people living with HIV, or know your rights programmes for LGBTI people to claim the HIV services in public hospitals (Clayton et al., 2014).

That said, there are debates in other disciplines of interest when analysing this role. Vernacularisation emerges as the area of literature that most directly refers to the role of social movements, NGOs and other non-state actors in the appropriation of international norms and therefore represents one of the pillars of the theoretical framework of this thesis, in particular when describing the development and strategies of CBOs of people at higher risk of HIV. As with a large portion of norm diffusion literature, vernacularisation often chooses human rights norms to analyse this role rather than global health norms such as HIV norms. Levitt and Marry focus their study of vernacularisation on the local uses of global women's rights. For these authors, local non state organisations, such as NGOs, act as facilitators of the

adaption of ideas generated by human rights and feminists movements to fit local contexts (Levitt and Merry, 2009). For Merry, “[A]ctivists from many countries enthusiastically adopt human rights language and translate it for grassroots people. Vulnerable people take up human rights ideas in a wide variety of local contexts because these ideas offer hope to subordinated groups” (Merry, 2006a:56). This area of literature confers an important role on local NGOs in the appropriation of global norms at the local level but it does not analyse the connection between the appropriation and localisation of international norms by local actors, such as CBOs, and the influence these actors have on the diffusion of these norms. This thesis contributes to addressing this gap in literature.

Vernacularisation also considers NGOs, along with cosmopolitan elites and beneficiaries themselves as vernacularisers, translators of global ideas into local contexts often marking a divide between transnational, national and local activists, exacerbated by differing understandings of cultures and values (Merry, 2009; Tarrow, 2005). According to Levitt and Merry, two main dilemmas ensue. First, a resonance dilemma whereby to have impact human rights ideas must be adopted locally so that they resonate with existing local ideologies. This claim relativizes the conviction that it is the universality of human rights principles which make them powerful (Risse and Finnemore, 2009) and defends the notion that localisation plays a central role in the diffusion of international norms (Acharya, 2004; Brown, 2014). Second, the advocacy dilemma: whereby when organisations align their advocacy on human rights with existing issues and strategies, they are “more readily accepted but represent less of a challenge of status quo” (Levitt and Merry, 2009: 458). This thesis challenges these assumptions about resonance and advocacy. In the empirical chapters, the thesis demonstrates that the CBOs of people at higher risk of HIV studied tend to appropriate international human rights norms with a low degree of adaptation to the local context and can potentially influence states to appropriate norms that could indeed challenge the local status quo dramatically.

In addition to vernacularisation, a significant part of the literature looking inwardly to CBOs of people at higher risk of HIV focuses on the role human rights principles and pursuits have contributed to the development and these CBOs. This analysis is particularly useful for this thesis when describing the characteristics and the development of the CBOs presented in the case studies, and the nature of the appropriation of international norms by their members, even when these authors do not directly refer to norm diffusion theory. Literature is particularly prolific in describing the role of HIV in the development of the international LGBTI

movement and how this movement for the human rights of sexual minorities has often run parallel and intertwined with the HIV movement, especially in the West where LGBTI populations had been organised in demanding their human rights since the early 1970s. LGBTI organisations and activists were at the core of the first movements of people living with HIV, including ACT UP in the US, Health Gap in the US and internationally, TAC in South Africa (Rom, 2000; Robins, 2004; Smith and Siplon, 2006; Fee and Parry, 2008), and in countries where the HIV epidemic was mostly concentrated in MSM and transgender people or where LGBTI populations have been most persecuted (Roberts, 1995; Torres-Ruiz, 2011).

Johnson describes some of the most prominent national LGBTI organisations in Africa providing HIV services and advancing LGBTI rights, including GALZ in Zimbabwe, Ishtar in Kenya, Frank and Candy in Uganda, or *Arc-en-Ciel* in Côte d'Ivoire (Johnson, 2007). Amory and Tamale, among many other authors describe the development of homosexual identities and of organisations representing these identities, which often provide HIV/AIDS services as one of their main activities (Dynes and Donaldson, 1992; Amory, 1997; Tamale, 2011; Frost and Meyer, 2012). Translated to the norm diffusion theoretical framework, these authors offer grounds to defend both the influence of CBOs of HIV affected populations in the diffusion of HIV and human rights norms and the role that appropriation of both HIV and human rights norms by CBO members has had in the development and strengthening of these CBOs.

However, analysis of the development of grass-roots organisations of populations at higher risk of HIV other than the LGBTI population and the relationship between HIV and human rights among these organisations is considerably scarcer. Likewise, there is little analysis on the use of international HIV or human rights norms these organisations make, or comparative studies among the various populations at higher risk of HIV as to their exposure to international norms. In the case of people who use drugs, authors tend to pinpoint the lack of social capital of this population in that it tends to lack resources to “organise collectively to facilitate coordination and cooperation for mutual benefit” (Putnam, 1995: 67; Rhodes et al., 2005). Literature on grass-roots organisations of injecting drug users focuses mainly on how they organise to reduce the risk of transmission of HIV (Benny et al., 1996). Friedman et al, describe the development of a drug users movement parallel to the HIV movement from the late 1980s which led to the creation of the International Network of People who use Drugs, INPUD, and regional networks, such as the Asian Network of People who Use Drugs, ANPUD, loosely affiliated to INPUD (Friedman et al., 2012).

Regarding sex workers' organisations, authors often dissociate the development of sex work movements and that of the movement on violence against women, focusing on the specificity of the sex work movement's calls against criminalisation of sex work, and anti-human trafficking legislation punishing sex workers entering sex work by choice and not by coercion. These calls contrast with some feminist discourses for the abolition of sex work, considered a manifestation of the exploitation of women (Doezema, 2001; Shah, 2011). The study of the mobilisation of sex workers is often circumscribed to women sex workers and not to male or transgender sex workers, the latter being severely under-represented in the literature on the mobilisation of people affected by HIV (Kempadoo and Doezema, 1998; Baral et al., 2012).

The rapid spread of the HIV epidemic among sex workers has had the side effect of organisations of sex workers in most affected countries finding a voice in the international sex work movement. The Sex Worker Education and Advocacy Taskforce (SWEAT) from South Africa, is a good example in this regard (Kempadoo, 2003). HIV and AIDS have also given some agency to sex workers organisations at the national level, although such growing influence has been largely cemented in the public health notion of risk behaviours and the false attribution of an identity to this population as a risk group (Siddharth, 2000). Altman warns about the over identification of risk groups and risky practices that make certain populations more vulnerable to HIV with common identities shared by members of these populations, while nevertheless noting that where people can organise around particular identities this can be the most powerful force for prevention and action against stigma (Altman, 2005). This thesis provides ample analysis of the relationship of members of the CBOs studied among themselves and with their organisation in terms of identification, motivations, expectations, and the role of the appropriation of both HIV and human rights norms by CBO members.

Conclusion

Norm diffusion theory is the main pillar of the theoretical framework of this thesis. This corpus of literature is of great importance in IR theory, which places the study of the diffusion of international norms at its core. Particularly over the past 30 years, norm diffusion literature has developed an understanding of how international norms travel from the moment they emerge to the moment they are adopted by states. Although some authors have analysed the later stages of norm diffusion, recognising that there is a process of adaptation of international

norms at the local level, literature is still developing an understanding of three key areas of norm diffusion at that later stage of implementation.

Firstly, most authors in the area of norm diffusion analyse the international human rights system, which has generated a robust governance of international human rights norms over the past decades. But authors often take for granted that the end-point of the process is the integration of international norms into the national practice of state actors and structures, without questioning whether there can possibly be local practice of implementation of international norms generated by non-state actors contributing to domestic practice along with state-led practice. Secondly, norm diffusion literature does not focus on analysing the factors that influence state behaviour at the level of norm implementation once it has appropriated, localised or rejected an international norm, in particular, the role that local actors play in influencing such behaviour, and the factors which intervene to make states re-position themselves in relation to a particular international norm. Thirdly, norm diffusion literature generally does not analyse fully the interaction between related norm diffusion processes, especially as to how this interaction may affect state behaviour.

Global health literature emerges as an important area of theoretical debate which helps address these gaps, and is therefore a second key pillar in this thesis' theoretical framework, mostly because it recognises an important role of international and local non-state actors in the generation and implementation of global health norms. In particular, global health scholars recognise the pivotal role that CBOs of people affected by HIV play in the implementation of HIV norms and analyse the embracing of human rights norms among members of these organisations, especially in the forging of common identities and advocating for their human rights. However, global health literature still presents some of the main gaps observed in norm diffusion literature. The prominent role of civil society organisations in global health literature and HIV within it is often circumscribed to their participation in public health policies laid down by the relevant state structures (ministries of health, national AIDS commissions, in some countries, AIDS programmes reporting to the president of prime minister's office...) that is, as contributors to national practice. Global health literature does not usually consider the possibility of these organisations generating their own practice outside or in contradiction with national health responses led by the relevant state structures. It also provides limited analysis as to the relationship between international HIV and human rights norms as to how norms from global HIV/AIDS governance penetrate norm diffusion processes in the international human rights system and vice versa.

Vernacularisation theory is also an important component of this thesis' theoretical framework as it makes a significant contribution to understanding the role of social movements and grass roots organisations, including CBOs, in the adaptation and appropriation of international norms among their members. This analysis is entirely relevant to study the appropriation of international HIV and human rights norms by CBOs of people at higher risk of HIV. However, like in global health literature, vernacularisation theorists do not undertake this analysis in the context of state behaviour. If indeed CBOs of people at higher risk of HIV are so critical to the implementation of these norms, it is essential to fill the analysis gap as to the role these organisations may or may not have in influencing the states where they operate to first appropriate these norms, and then ensure their implementation by complying with and enforcing them.

The combination of the in-depth analysis in norm diffusion theory of how international norms travel from the international to the national level, the analysis by global health literature of CBOs as implementers of international HIV norms, and the considerations of social movements, NGOs and CBOs as vernacularisers of such norms translating them to the local level, offer the conceptual framework for the following chapters, which describe in detail the empirical analysis of this thesis as to the role of the CBOs of people at higher risk of HIV studied in the diffusion of international human rights-based HIV norms domestically, through their own local practice using these norms in the responses to HIV they provide, influencing the national practice of their government and other state actors or both.

3. AN EMPIRICAL ANALYSIS OF COMMUNITY-BASED ORGANISATIONS IN THE DIFFUSION OF INTERNATIONAL HUMAN RIGHTS-BASED NORMS

Introduction

This chapter introduces the main points of discussion and areas of exploration which formed the basis for the empirical analysis undertaken through the field research, presented as case studies in the next four chapters. This analysis was framed following the parameters offered in norm diffusion, global health, vernacularisation and related IR literature as the basis for the theoretical framework described in the previous chapter with the aim to present evidence to contribute to the central research question of the thesis: what role can CBOs of people at higher risk of HIV play in the diffusion of human rights-based HIV norms domestically? The main points of analysis associated with this central point aim to provide evidence as to: 1) whether the CBOs studied can generate their own local practice based on their embracing of human rights-based HIV norms; 2) whether these CBOs can influence positions of some key external and/or internal actors in the diffusion of international HIV and human rights; and 3) what lessons can be learned about the interrelation between international norms as a result of analysing the strategies of the CBOs studied to try to influence various norm diffusion processes simultaneously.

Regarding the central research question, the four empirical chapters of this thesis gather evidence to make a case for the inclusion of a new set of local actors which are often overlooked in norm diffusion literature. Although much of the study of actors in the diffusion of international norms is based on states and on proponents or opponents to particular norms, including NGOs (Krook and True, 2010; Stoeva, 2010), CBOs at the grassroots level constitute a crucial layer between these actors and individuals for whom these norms are intended with a critical role in explaining how these norms travel to the local level. Firstly, the empirical analysis helps further the study in norm diffusion literature of the appropriation of norms which most of the norm diffusion theory attributes solely to states (Stoeva, 2010; Acharya, 2004; Brown, 2014) and contributes to the study undertaken by vernacularisation scholars as to the role that local actors such as CBOs play in diffusing and translating international norms in such a way that they can be owned by the populations they represent (Merry, 2006). Secondly, the case studies enquire the role of CBOs in each country exploring if these organisations are indeed essential implementers of international human rights-based norms. Critically, if these

CBOs undertook their interventions following their own strategies, and not as implementers of state-sanctioned policies as part of the national response to HIV, therefore not just as contributors to national practice, these CBOs would be generating their own local practice providing a unique contribution to the domestic practice of human rights-based norms to tackle HIV. This would question the consideration in norm diffusion theory of national practice as the sole end of the diffusion of international norms, at least as far as the diffusion of international HIV norms is concerned.

The second area of empirical analysis contributing to the central research question focuses on the degree of influence the CBOs of people affected by HIV studied have had on key external and/or internal actors in the diffusion of international HIV and human rights, and on their governments and relevant state actors (such as the judiciary or members of parliament) in charge of articulating of state's positions in relation to international norms. In order to contribute to dynamic interpretations in literature of international norms evolving as they are diffused (Risse and Sikkink, 1998), the thesis explores CBOs' influence even after such norms have been being adapted to the local context (Acharya, 2004; Krook and True, 2010; Brown, 2014). In this respect, the empirical analysis also tries to help understand whether the key state actors responsible for the integration of international norms into the state's national practice do actually do so and how this integration evolves in time. The four case studies explore various degrees of CBO influence over external and internal actors, ranging from very limited to being able to force their governments to overturn their rejection of a particular international norm to the point of becoming champion proponents of that very norm.

The final area of empirical analysis in this thesis explores the strategies of the CBOs analysed in relation to the diffusion of international norms from more than one governance system (particularly, human rights norms from the international human rights system and HIV norms from global HIV/AIDS governance) with the aim to contribute to filling a significant gap in norm diffusion literature as to how related norm diffusion processes from different international governance systems actually influence each other. The case studies explore whether the CBOs studied can apply their agency in one process (for example, international HIV norms for the response among drug users) to influence other processes (for instance, international drug policy norms to fight illegal drug use). The states analysed in the case studies behave differently in relation to concurring norm diffusion processes. This means that either the government and other state representatives constantly contradict themselves, or the state is represented by different institutions in the governance systems where each process belongs (in the previ-

ous examples, the state could be represented by the Ministry of Health in the case of HIV norms, and by the Ministry of Interior in the case of drug policy) the latter contrasts with the wide consideration of states as a single actor in norm diffusion literature (Nadelmann, 1990; Cortell and Davis, 2000; Stoeva, 2010).

Some authors have alluded to competition between international norms, but they have largely circumscribed to norms within a given international governance system (i.e. international HIV norms in global HIV/AIDS governance; international human rights norms in the international human rights system; international drug policy norms in global drug policy governance) competing at the international level when norms are being socialised mostly by states (Meyer et al. 1997; Reus-Smit, 2009). Some of the case studies explore what takes place when the state commits to implementing two international norms from different international governance systems which oppose each other on the same normative issue and what the resolution of such clash tells us about hierarchies between international norms and among the key actors involved the diffusion of such norms.

How critical are CBOs in the diffusion of human rights-based HIV norms?

The main area of empirical analysis undertaken in this thesis is about the role that CBOs of people at higher risk of HIV actually play in the diffusion of human rights-based HIV norms. In this respect the description of the roles of CBOs provided in the case studies of this thesis makes a strong case for the thorough analysis of a new set of local actors –CBOs– in the study of diffusion of international norms all the way to their integration into domestic (local and national) practice. Firstly, the case studies explore the role CBOs play in the implementation of HIV norms as they are key providers of HIV services and programmes among the populations they represent. This is particularly relevant in the case of the marginalised populations described in the case studies. State representatives recognise that state institutions often cannot reach these populations because they are hidden and because they do not trust public health services. These institutions therefore have to rely on CBOs to carry out peer-to-peer interventions to provide such services, subcontracting such organisations to respond to the HIV epidemic among the populations they represent. As shown in the previous chapter, this role as contributors to national practice is widely recognised in global health literature (Reza-Paul et al., 2008; Mburu et al., 2012; Harman, 2012).

This situation highlights a key characteristic of global health norms which makes these norms particularly interesting in norm diffusion literature, as these norms are often in the form of good practice extending to all health care practitioners, not only public health care providers. This nature is well described by Kamradt-Scott, although this author refers more to norm entrepreneurs such as the WHO with a strong global presence and not to local actors implementing global health norms at the local level. This is also a noticeable oversight in norm diffusion literature, which tends to equate norm implementers solely with states, the only entities that norm diffusion refers to as “norm takers” in charge of complying with and enforcing international norms (Kamradt-Scott, 2012; Checkel, 1998; Acharya, 2004; Björkdahl, 2005; Domínguez 2010). The role of CBOs in the implementation of international HIV norms described in the case studies makes a case as to the importance for literature to incorporate actors other than states when analysing how international norms are implemented domestically, locally and in national practice as the latter is a central objective of any norm diffusion theory (Cortell and Davis, 2000; Krook and True, 2010).

Although there is ample global health literature on the need to address human rights barriers in the response to HIV and AIDS to be effective in ending the pandemic (Piot et al., 2009; Schwartländer et al., 2011; Clayton et al., 2004), much as in the case of norm diffusion literature, global health literature tends to underrepresent the role of CBOs as implementers of international human rights-based HIV norms and often circumscribes this role to advocacy and campaigning (Robins, 2004; Smith and Siplon, 2006; Nunn et al., 2012). The seven UNAIDS programmes most referred to as those describing human rights-based HIV programming are focused on the direct relationship between the individual and public institutions. These interventions roughly correspond to the four levels of change pursued with HIV interventions that are common in HIV programming literature known as the Ottawa Chapter for Health Promotion: changes at individual level (legal literacy, HIV related legal services), changes in community, social and cultural values and norms (stigma and discrimination reduction programmes and programmes to reduce gender inequality, harmful gender norms and gender-based violence); changes in health and support services (training of health care providers); and changes in laws, policies and other structural factors (sensitisation of law makers and law enforcement officials; and monitoring and reforming laws, regulations and policies relating to HIV) ((UNAIDS, 2012b).

The case studies describe how some CBOs provide other services which members consider critical in ensuring that human rights-based responses to HIV are sustained. These

services are often left out of the classification of human rights-based HIV programming, and therefore often go under-researched and underfunded. These include the safety and security of CBO members, and emergency responses to cases of human rights abuses provided by CBOs, such as safe accommodation or psychological support, which as the case studies describe, occupy a large portion of the time and efforts of CBOs of populations at higher risk, even though much of this activity is often carried on an *ad hoc* basis and without structured programme management protocols (Restoy et al., 2015).

The thesis shows numerous examples of the devastating effects of purely pharmaceutical considerations on communities of affected populations turning government policies towards public health principles based on safeguarding the health of the majority even to the detriment of the wellbeing of a minority rather than human rights ones upholding everybody's basic rights. However, the case studies challenge authors' perceptions that this biomedicalisation in global HIV/AIDS governance translated at the national level continues to decimate the agency of NGOs and CBOs when it comes to implementing human rights-based HIV policies (Seckinelgin, 2008; Nguyen, 2010). The ever growing concentration of HIV epidemics in highly stigmatised populations in the cases studied in the thesis plays into the hands of CBOs representing these populations in terms of their agency as it is increasingly obvious that blanket public health principles that focus on the majority of the populations and ignore the most marginalised groups will not work to end AIDS.

Here is where human rights and public health approaches to the HIV response intersect. Even when global HIV/AIDS governance is still heavily biomedicalised, there is much more consideration for critical enablers of the HIV response (social, legal, political), which also call for community participation and the application of human rights principles and norms (Schwartländer et al., 2011; Global Fund, 2013). The case studies present examples of various entry points for CBOs of populations at higher risk to introduce human rights principles to the HIV response. These opportunities firstly arise from the evolution in most regions, excluding large parts of Southern and Eastern Africa, of the HIV pandemic itself, extending among populations at higher risk, and also the way the HIV response has passed from one where treatment was at the core of all interventions, to one where HIV prevention has become equally important. The case studies analyse whether this shift has also translated in the most concerned parts of government, ministries of health mainly, to try to reach out for civil society organisations providing services to marginalised groups and CBOs of populations at higher risk of HIV in the cases analysed.

How important is norm appropriation among the populations CBO represent?

After exploring how the CBOs analysed contribute to the implementation of human rights-based HIV responses, the case studies focus on two main points: can the CBOs studied generate their own local practice based on their embracing of human rights-based HIV norms. For this, the case studies look into what effect CBOs' responses to HIV based on human rights have among the population they reach in terms of how this population understands and values the principles of the international norms these interventions are based on. Both of which would indicate that members are embracing such norms. The case studies then explore if this perception represents the basis upon which these organisations design their objectives and strategies to provide human rights-based responses to HIV and trying to influence government policy. This line of analysis helps revisit the widespread assumption in norm diffusion literature that states are the central subject of norm appropriation (Stoeva, 2010; Acharya, 2004; Brown, 2014). In this respect, the thesis enters the domain of vernacularisation theorists who study in depth the role of local actors such as social movements in the adoption of international norms and principles making the case for such analysis to also be considered in norm diffusion theory (Merry, 2006).

The empirical analysis chapters explore two major elements which would favour the role of CBOs of people at higher risk of HIV in fostering the embracing of international norms among the populations they represent: 1) personal empowerment and increased self-esteem that the knowledge of human rights norms and principles provide, and 2) identification with peers. Human rights norms and principles championed by the CBOs of people at higher risk of HIV analysed play a significant role in individual members' self-esteem and sense of personal purpose. For most of the CBO members interviewed, knowing about human rights principles and the human rights system has deeply contributed to their personal journey, being a vehicle to stay healthy, to relate to their own families and friends, or to confront violence and social discrimination.

This scenario, where international human rights norms and principles play a role in the empowerment and self-esteem of members of the CBO of populations at higher risk studied, contrasts with how authors describe the personal positioning of people at higher risk of HIV towards the disease. Nguyen describes how a sort of therapeutic citizenship emerged among people living with HIV, especially in the early days of the epidemic, when coming out as a HIV positive person was both a statement of belonging to a new social group and a survival strategy

to show up and be counted to access life-saving treatment. However, Nguyen also sees the development of a moral economy bringing a strong sense of solidarity to people living with HIV (Nguyen, 2010). The case studies in this thesis are a good illustration of how this moral economy translated into the coming together of people living with HIV beyond mere solidarity and on to an activism aimed to influence the diffusion of human rights-based HIV norms.

Testimonies collected among CBO members interviewed for the case studies place human rights principles at the centre of their motivations to both stay together as groups and to carry out volunteer HIV work, including peer-to-peer interventions, where human rights become a crucial tool in reaching out for other marginalised groups with HIV programmes. However, the empirical analysis needed to ascertain the degree to which these CBOs had adapted (translated) these standards for their members. The low level of modification of such principles to conform to the local context by the CBOs identified across the four case studies is consistent with the sense of empowerment these principles give CBO members as opposed to a local context of marginalisation and exclusion. This circumstance backs constructivist theories as to how international norms prevail over bad local beliefs and practices (March and Olsen, 1989; Wendt, 1999; Nadelmann, 1990) and invites to question the role of social movements and organisations, including CBOs, as translators to local realities of international norms defended in vernacularisation theories to the point of adapting them to local principles and even abandoning reference to the international language in the process (Levitt and Merry, 2009).

This low level of translation also calls for the revisiting of the resonance dilemma in vernacularisation theory whereby to have impact human rights ideas must be adopted locally so that they resonate with existing local ideologies (Levitt and Merry, 2009). If international principles which challenge the status quo resonate among CBOs members, would not this be a strong incentive for CBOs to strive to try to influence their government and other authorities to try to change such status quo? Merry indeed points to the traction these principles could have among social movements and other civil society actors: "Vulnerable people take up human rights ideas in a wide variety of local contexts because these ideas offer hope to subordinated groups" (Merry, 2006a:56). This quote resonates with the constructivist notion that it is actually the universality of human rights principles, and not necessarily their translation into the local context which make them powerful (Risse and Finnemore, 2009).

The case studies look in detail into the role international norms and principles in strengthening of the sense of identification of members of CBOs they represent. The interviews

carried out among CBO members indicate that these norms help strengthen the bond that CBO members develop with their peers through shared experiences of vulnerability in relation to HIV and AIDS or similar experiences of social exclusion and discrimination and exposure to human rights violations. However, these testimonies also indicate serious categorisation issues when identifying individuals with the CBO which represents them. The case of LGBTI organisations studied is particularly illustrative. These organisations often represent a myriad of individuals opposing stigma and discrimination on the grounds of sexual orientation or gender identity. They often fight together against the criminalisation of same sex relationships but that same goal does not mean all its members belong to a single community, that of LGBTI people.

Lesbian women interviewed in Uganda, for instance, do not generally have a specific sense of identification with gay men but tend to have more affinity with transgender men, who in their turn aim to assert their masculinity and dissociate from women. These differences make even more incongruous the identification of HIV literature of populations at higher risks as communities, especially when these communities refer to medical behaviour, such as MSM, rather than personal and social identification with a particular community (Blackwood, 1996; Johnson, 2007; Frost and Meyer, 2012).

The empirical analysis therefore questions the rationale in the adoption by CBOs of international constructs of identity, exploring whether the CBOs studied have to adapt their strategies to these classifications either to get funding from global HIV/AIDS governance or to advance their advocacy positions. This positioning may have negative effects on the cohesion of these CBOs and on the identification of members with the CBOs which represent them. For instance, the case study on transgender organisations in Honduras questions the validity of putting of all the LGBTI population in one basket as regards to HIV programmes, which means that larger LGBTI organisations, the vast majority of which are managed by gay men, tend to administer funding also for transgender women, centralising all the HIV response and debates about LGBTI rights on the issues of MSM, thus disempowering transgender people.

The theoretical framework chapter highlights that the biomedicalisation of the HIV response tends to focus on the individual relationship between the service provider and the patient, often relegating the role of CBOs to passive agents with largely tokenistic roles in HIV/AIDS governance and creating new biomedical communities, such as MSM, or drug users, as patients with similar risk patterns of HIV transmission often as the only common

characteristic regrouping them. The empirical chapters explore the validity of such biomedical constructs and their resonance among members of the CBOs analysed. In the case studies, very rarely do behaviours (sexual, drug intake, or others) or heightened risk to HIV explain the identification of CBO members with each other and with the organisation that represents them. However, people at higher risk of HIV have learned to refer to themselves along the lines of these biomedical communities to their advantage to guarantee a sustained response to HIV by the CBOs which represent them. For example, most LGBTI organisations providing HIV services studied in Uganda present themselves as organisations of MSM, when approaching HIV funders or other actors. This despite the fact that in reality there are very few of these organisations formed exclusively of gay men.

Can CBOs of people at higher risk of HIV influence key actors and their governments' positions on international norms?

As the case studies explore the role the CBOs studied play in the application of human rights-based norms to the responses they provide to HIV among their members, these chapters also explore whether this role has been recognised by key actors in HIV/AIDS governance and the human rights system as well as by in key internal actors and ultimately key state representatives. This influence among key actors grows from case study to case study. Firstly, international donors and other external actors of the HIV/AIDS governance, provide the technical and financial resources necessary for the CBOs of populations at higher risk studied in the thesis to be stronger organisations which are better equipped to apply human rights principles to the HIV response they provide. This relation between local actors and external proponents of international norms is well indicated in norm diffusion theory (Keck and Sikkink, 1998; Finnemore and Sikkink, 1998). Norm diffusion authors describe this connection as local actors linking up with international TANS who according to them are the ones with the agency to influence norm diffusion, largely disregarding the possibility for local actors to also influence the process (Keck and Sikkink, 1998).

Global health literature also shows an uneven relationship between international NGOs and CBOs in the global South, often regarded as local partners implementing the programmes and guidelines set in the North (Seckinelgin, 2005; de Waal, 2006), and therefore effectively denying significant agency among CBOs to influence decisions by key external actors such as international governance agencies (UNAIDS or WHO in the case of HIV/AIDS gov-

ernance) or donors. The case studies explore whether this is indeed the case of the CBOs of people at higher risk of HIV analysed or whether these CBOs build agency as well. Although the CBOs studied cannot control or dictate what international NGOs, governments and other institutions do or say about their own human rights context, they try to utilise this international force as part of their own strategies to appropriate human rights norms. For instance, LGBTI organisations in Uganda created parallel internal discourses that do not claim LGBTI rights (as campaigned by international LGBTI organisations), but rights for all, with which to rally a number of mainstream organisations while calling for international support strategically when they consider that international pressure should be exerted.

The CBOs studied in the thesis also seek to gain support among potential internal proponents. The case studies show that some of these CBOs carry out both strategies simultaneously, as decisions by internal and external actors are often interdependent. All case studies in the thesis highlight the complexity of multiple political implications of the HIV response among norm takers and how they impact on the human rights-related strategies taken by the CBOs of populations at higher risk studied. The case studies look into the role that HIV has played and may continue to play in partisan politics and in the foreign policy of the countries analysed. El Salvadorian government, for instance has made HIV a key element of their foreign policy through the promotion of the provision of universal access to antiretroviral drugs. In other countries such as Uganda, the HIV response has been highly criticised internationally, especially in cases of mismanagement of HIV funding or when populations at higher risk of HIV are perceived to be discriminated against in this response, or when they are perceived to suffer human rights violations in law or practice. This has affected their diplomatic relations with other states and at times, compromised the arrival of international donors' funding to fight the HIV epidemic. It has also provided an opportunity for the Ugandan CBOs studied to leverage their human rights and HIV objectives, exposing governments' shifts in their HIV-related policies which often contradict their own public health and human rights principles.

These contradictions indicate that human rights-based responses within the HIV/AIDS governance alone may not safeguard the human rights of populations at higher risk and the sustainability of human rights-based responses to HIV among these populations. The case studies describe how some of the CBOs analysed embrace human rights norms and adapt their human rights language strategically while trying to negotiate contradictions in government policies regarding the population they represent. Adaptation strategies explored throughout the case studies include: appealing to mainstream human rights organisations and other civil

society organisations around corruption, maternal health or other general issues, calling on international pressure when deemed strategic, collaborating with governments, or focusing only on public health for some time to reduce tension around controversial human rights principles perceived by some as foreign impositions.

Finally, the case studies explore whether the CBOs analysed manage to influence their government to the point of overturning its decision to appropriate, reject or modify a particular international norm. El Salvador case study shows that CBOs of people living with HIV indeed made the government change their policies regarding the provision of ARV treatment, from denying such treatment on the grounds of high cost to providing it for free in conformity with international human rights-based HIV norms. This empirical evidence of the influence that CBOs of people at higher risk of HIV may have on the position of key state actors (government, relevant ministries, like health or social affairs, national AIDS commissions, the judiciary, members of parliament, etc....) towards international norms is of significant importance in the study of the theory of norm diffusion in two main ways. First, it makes a case for norm diffusion to pay particular attention to the role of local non-state actors, such as CBOs, in influencing positions of states in relation to a particular international norm. Acharya and Brown highlight the importance of the phase of norm diffusion when international norms are modified to bring coherence to the local context. However, both authors focus their analysis on the adaptation carried out by states and local leadership, not so much the role of non-state actors at that level. Acharya does consider other local actors in the reconstruction that states make of international norms but not to the point of influencing decisions made by the state (Acharya, 2004; Brown, 2014).

Second, the potential influence that local actors such as CBOs may have on the decisions made by governments and relevant state actors in relation to international norms makes it necessary to consider the diffusion of international norms beyond the moment when the relevant state representatives decide to commit to a particular international norm on behalf of the state. This influence would trigger a boomerang effect later in the process of norm diffusion, already at the local level, inviting to question the circumscription of such effect to the earlier phase of international socialisation of norms described by Keck and Sikkink, who argue that at that stage non-state actors within the jurisdiction of these states can connect with international actors, including other states and international NGOs advocating for a particular norm, to persuade or force representatives of the state in question to adopt the norm (Keck and Sikkink, 1998).

Local competition and hierarchies in international norms

International norms often clash, particularly when they belong to different governance systems. For example, international drug policy norms consider drug users as delinquents, whereas human rights-based HIV norms would treat them as patients. Often states commit to adopting opposing international norms at the same time. For this reason, CBOs may try to influence more than one norm diffusion process at the same time. The case studies explore the combination of strategies laid down by some of the CBOs analysed to simultaneously interact with various related norm diffusion processes belonging to various international governance systems. The empirical analysis of this interaction offers valuable points of reflection about how these international norm diffusion processes may affect their respective outcomes, and about hierarchies among international norms, the governance systems they belong to, and the internal and external actors involved.

The case studies describe several instances of two or more international norms competing over a single normative issue which inevitably leads to one norm being effectively complied with and implemented by the government and relevant state actors to the detriment of the competing norm. This circumstance makes yet another case as to the importance of studying the later stages of implementation of international norms to help analyse the hierarchies of international norms within norm diffusion theory since norm diffusion literature tends to narrow its focus about norm competition to the early stage of international socialisation between states and external proponents, not at the local level (Meyer et al., 1997; Finnemore and Sikkink, 1998). The case study on CBOs of drug users, for example suggests that in the case of Ukraine it is international drug policies which are implemented to the detriment of international harm reduction norms and invites to analyse the apparent prioritisation by the government of the former over the latter, illustrating the consideration in global health literature that “health policy has often been seen as an arena of “low” or “soft” politics that is somehow a side issue to more “hard” or “high” policy areas such as conflict, security, development and the economy” (Haman, 2012:3).

As pointed out earlier, the case studies describe how, in order to be able to overturn the positions of state actors in relation to international norms, most of the CBOs studied try to influence both internal actors, including the government and key state actors and external actors such as international donors. When attempting to do so in more than one norm diffusion process at the same time, these CBOs identify for each process the various structures,

institutions and individuals within the state and among internal and external actors. Logically, the CBOs analysed try to influence the state actors which could be more lenient to their positions (for example, Ukrainian organisations of people who use drugs try to influence the Ministry of Health on harm reduction norms to respond to the HIV epidemic, trying to avoid the Ministry of Interior). These strategies question the widespread consideration of both states and external actors in norm diffusion literature as monolithic structures presenting just one consistent position in relation to an international norm (Nadelmann, 1990; Cortell and Davis, 2000; Stoeva, 2010), with the significant exception of Risse and Sikkink who acknowledge diverse roles for various states structures in effecting the changes that international norms should bring to the domestic normative, political and institutional developments (Risse and Sikkink, 1999).

Some of the case studies provide examples of interferences between international norm diffusion processes from HIV/AIDS governance and the human rights system opening an important avenue to reflect on the side effects of the inconsistency of donors' policies. To date, the bulk of the bilateral support that the CBOs of populations at higher risk of HIV studied receive from donors comes from embassies and ministries of foreign affairs, that is, from the political/human rights parts of governments, whereas it is normally multilateral donors which support the provision of HIV interventions by these CBOs. This support reflects the intertwining of processes of norm diffusion from the HIV and human rights governance systems and exposes inner contradictions between foreign and international development policies in international donors which have been thoroughly studied by authors and recognised by some donors, including the European Union (Van Schaik and Egenhofer, 2006; Carbone, 2008). Examples of human rights contradictions in the HIV policies of donors are numerous throughout the thesis, but perhaps the most descriptive one is the case of Uganda, whose government receives the bulk of its funding for the HIV response from international donors, despite severe gender inequality and widespread state-sponsored violations of the human rights of the LGBTI population and other populations at higher risk of HIV consistently denounced by most governments financing such response.

The main focus of the empirical exploration undertaken by the thesis in this area is the contradictions governments show in their positions regarding human rights-based responses to HIV. All populations at higher risk of HIV studied in the case studies suffer severe legal and policy discrimination and social rejection and stigma and are exposed to human rights violations committed by representatives of the very state which has pledged to provide a HIV

response respectful of the human rights of these populations. The clash between norm diffusion processes under HIV/AIDS governance and drug policy governance explored in the case study on CBOs of drug users in Ukraine is particularly illustrative. CBOs of drug users find themselves negotiating between health authorities promoting services for these populations and donors funding rights-based programmes for drug users on one hand, and the Ministry of Interior and other powerful parts of government persecuting drug users as a threat to national security on the other.

Conclusion

The empirical analysis presented in the next four chapters explores the role that the CBOs of populations at higher risk of HIV analysed play in the diffusion of human rights norms as applied to the HIV response. The case studies explore how some of these CBOs play this role as these organisations are essential providers of the services and programmes which implement such norms among the populations they reach, a role that is thoroughly highlighted in global health literature but not considered in norm diffusion literature.

The empirical analysis also studies the embracing of international human rights norms and principles by members of the CBOs analysed and whether these norms are in fact at the core of the objectives and strategies of these organisations. This analysis enters the domain of vernacularisation theory as it enquires whether CBOs are indeed essential to translate for international human rights norms to reach people at higher risk of HIV so that they appropriate such norms, feeling empowered to use the human rights system to realise their rights.

The case studies focus extensively on some of the strategies the CBOs studied undertake to both ensure the application of human rights-based norms in the domestic HIV response among the population they represent, and to influence the government and other key state actors regarding such norms. This analysis makes a case for norm diffusion literature to further study the role of non-state actors in the diffusion of international norms. The case studies explore whether these CBOs generate their own local practice by implementing human rights-based HIV norms regardless of or even bypassing the government when it rejects such norms, whether they influence key internal and external actors and whether they manage to influence the government and key state actors to introduce such norms in their own policies, thus influencing national practice in the domains of HIV and human rights.

The simultaneous positioning of some of the CBOs studied in various diffusion processes of international norms belonging to different governance systems brings additional points of discussion and analysis of the inconsistencies that both states and external actors show in their behaviour regarding the diffusion of opposing international norms. The following empirical chapters explore these inconsistencies and the implications of various state and external actors being represented in different, at times competing norm diffusion processes, offering various points of analysis about hierarchies among international norms and among key actors in the diffusion of such norms.

4. NORM APPROPRIATION THROUGH IDENTIFICATION: TRANSGENDER WOMEN'S ORGANISATIONS IN HONDURAS

Introduction

This study on CBOs of transgender women in Honduras offers three main contributions to the empirical analysis on norm diffusion theory. Firstly, the chapter provides evidence of the central role that the CBOs of transgender people analysed in the case study play in the embracing of international human rights norms and principles by the population these organisations represent. This assimilation occurs in a context of generalised transphobia, violence and extreme marginalisation. Even when the transgender women interviewed often lack accurate knowledge of international human rights principles and norms, these norms play an important role in increasing the self-esteem and the sense of identity and security of these women as they face severe social exclusion. This empowerment effectively translates into transgender women benefiting from the application of international HIV and human rights norms that their CBOs provide through their interventions which, although limited in scale and resources, create local practice contributing to the domestic HIV response in Honduras.

If indeed the role of norm diffusion theory is to study how international norms affect national practice (Krook and True, 2010; Brown, 2014), this case shows how important the ownership of international norms can be for local actors other than states to ensure, albeit in a limited way, the application of these norms when the state does not comply with or enforce them. This circumstance highlights the need for literature to study actors (CBOs in this case) which make the translation of international norms into domestic (local and national) practice possible. It also brings attention to the later stages of norm diffusion, the implementation phase where norms are incorporated into national practice (Davies et al., 2015).

Secondly, the case study provides evidence of the inability of the transgender organisations analysed in Honduras to influence the government's compliance with and enforcement of international norms protecting transgender people it has committed to implementing, which also exposes the incapacity of these groups to influence the diffusion of international human rights-based HIV norms in the country. A first factor contributing to explaining this inability is that CBOs of transgender women in Honduras have very precarious structures, with limited resources and few dedicated and educated personnel. This reflects the little interest shown by HIV donors and human rights champions in supporting the

sustainability of these organisations. A second main factor is that these CBOs are unable to influence either external or internal non-state actors relevant to the diffusion of international norms. Transgender organisations are not considered key actors in the HIV/AIDS governance of Honduras even when they indeed play a crucial role in the provision of peer-to-peer services to transgender people. This means that these CBOs cannot leverage their position as norm implementers to gain agency to influence either external actors, such as donors, or internal actors to play their role in monitoring compliance of international standards by the government and other state structures.

The third main contribution of this case study relates to the part of norm diffusion literature more interested in the phase of localisation of international norms to conform to local realities (Acharya, 2004; Brown, 2014) and to vernacularisation theory. CBOs of transgender women embrace international human rights norms with very little adaptation to the local context for two main reasons: firstly, because, as it is often the case across Latin America, the state and local leadership have largely committed to adopting international human rights norms as they were conceived internationally, with very little contestation or modification to the local context; secondly, because these norms represent in themselves a rejection of social and cultural norms and beliefs that stigmatise transgender people. As a result, transgender organisations in Honduras play much less of a translator role whereby the spirit and content of international norms would be adapted to fit local beliefs making them more acceptable (Snow et al., 1986; Levitt and Merry, 2009) and more of a conveyer role of these international norms as the populations these CBO represents are attracted precisely by the opposition to the local status quo these norms represent.

Context: transgender women in Honduras, violence and HIV risk

A transgender person has a gender identity that is different from his or her sex at birth. Transgender people may be male to female (female appearance) or female to male (male appearance). Transgender people prefer to be referred to as 'he' or 'she' according to their gender identity, i.e. the gender that they are presenting, not their sex at birth (UNAIDS, 2011). This case study focuses on people born as male but who have a feminine gender identity, regardless of their physical appearance. They are referred to as transgender women in this text, although they often refer to themselves just as *trans*.³

³ This term is preferred because it is more inclusive of the various and changing types of gender identities of

The situation of transgender women in Honduras is one of maximum exposure to both HIV and to extreme violence, discrimination and social rejection. This context makes this population relevant in the context of both international HIV and international human rights norms and, given the strong relationship between these two areas, of international human rights-based HIV norms (Schwartländer, et al., 2011; Clayton et al., 2014). HIV literature states that in contexts like Honduras, organisations representing transgender people should be the core of the human rights-based response to HIV, with strong support from both states and external bodies of global HIV/AIDS governance, including donors (Johnson, 2007; Baral et al., 2009). As this case study describes, the precarious organisational situation of most CBOs of transgender women in Honduras shows that this is not the case.

The national HIV prevalence rate in Honduras is estimated to be 0.66% (*Secretaría de Salud*, 2010), however, prevalence rates among transgender women are estimated to be between 8.2% and 16% in Tegucigalpa and San Pedro Sula (Paz-Bailey et al, 2006). In Latin America, HIV prevalence rates among transgender people range from 25% in El Salvador to 35% in Argentina and Peru (IHAA, 2011a). Discrimination and persecution, violence, and sex work often push members of the transgender population into more risky sexual practices (Borgogno and Gabriel, 2009) and impede their access to HIV prevention programmes, rendering the HIV response highly inefficient.⁴

Transgender women are often expelled from their homes at a young age because of rejection by their families, including violence at the hands of families themselves when they discover the sexual orientation of the person, or by neighbours or other individuals. Most transgender people in Honduras do not go to, or are expelled from, secondary school because of prejudice about their sexual identity; they subsequently end up on the streets. Transgender women tend to concentrate in urban centres. Violence against transgender people is widespread. It is often described by Honduran LGBTI rights organisations as a hate crime (Cattrachas, 2012), defined as violence committed solely because of fear of, or hatred against, transgender people, known in literature as transphobia (Gender Equity Resource Centre, 2010), a concept adapted from homophobia, generally referred to as fear of, and hatred against, gay people (Amnesty International, 2001).

members of the transgender population and also because in the case of Honduras, most transgender women have not carried out a full surgical operation to reassign all their sexual organs, mostly due to lack of economic resources.

⁴ Interview with Under-Secretary of State for Justice and Human Rights, Tegucigalpa, 17 July 2012.

*The origin of generalised violence against transgender women is a triple assumption that causes repulsion in society: transgender women are homosexuals, prostitutes, and HIV positive. That puts us at the bottom of society.*⁵

Up to 95% of transgender women in Honduras engage in sex work. Transgender sex work takes place mostly at night and on the streets, in the case of San Pedro Sula, in four well determined areas. Some of these areas are controlled by the *pandilleros* or *maras* (armed neighbourhood gangs).

*In January 2012, a mara guy who was drunk pointed his gun at me and forced me to have oral sex with him while he was still aiming at me. I was terrified, I couldn't move for fear of being shot at. I noted down his motorbike's registration number but I haven't got the guts to present a complaint. I've seen him again in the streets with other mara people; he insults me and calls me 'culero' ['queer'].*⁶

Although none of the transgender women interviewed referred to it, sex work takes place in the streets at night, often in neighbourhoods that are controlled by the *maras*. It is hard to imagine that there is no involvement of organised crime, either to take a part of the benefit obtained from sex work in exchange for protection (the so called *impuesto de guerra*, war tax), or to sell drugs among sex workers and their clients, since these groups interfere with most economic activity in Honduran cities (US Department of State, 2011).

CBOs of transgender women: norm appropriation through identification

Although the notion of a transgender community is not so clearly articulated by the transgender women interviewed, the praxis of how the transgender organisations analysed have proliferated and developed shows a degree of cohesion and unity that could represent the emergence of a distinct transgender community in Honduras. This section demonstrates that this organisational development has been largely articulated thanks to the assimilation of international human rights norms, and to a lesser extent, international HIV norms. This fact departs from widespread considerations in both literature and among relevant actors of the international human rights system and global HIV/AIDS governance, of transgender people as belonging to a larger community of LGBTI people bonding through a shared identity based on

⁵ Interview with a transgender leader, San Pedro Sula, 11 July 2012.

⁶ Interview with a transgender sex worker, San Pedro Sula, 12 July 2012.

sexual orientation and gender (Amory, 1997; Tamale, 2011; Harper and Schneider, 2003; Frost and Meyer, 2012).

Often the larger Honduran CBOs and NGOs of LGBTI people include transgender women. However, some transgender organisations begun to break away from these larger organisations in the late 2000s. This case study focuses on transgender women's organisations in San Pedro Sula, El Progreso and Tegucigalpa. Most of the women interviewed belong to these organisations, either as workers or volunteers or as regular members. The vast majority of the members and personnel of these CBOs are street sex workers. With the exception of the director of the *Colectivo Unidad Color Rosa (Colectivo)* in San Pedro Sula, all workers interviewed are volunteers or work part time for a small stipend. The management and governance structures of these organisations are extremely weak due to the lack resources to pay professional staff and the difficulty of forming skilled and dedicated boards.⁷ Turnover of both volunteers and board members is high largely due to high mobility and high morbidity due to violence and AIDS prevalence in the transgender community.⁸

The key role these CBOs play in the diffusion of international norms originates in how they foster a sense of identification of transgender people with the CBOs. This identification is not based on identity although it is a common generalisation that lesbians, gays, bisexuals and transgender people represent one cohesive community, the LGBTI community. As mentioned earlier, this assumption is widespread among organisations and institutions of both global HIV/AIDS governance and the human rights system (for example, LGBTI Community Equality Network, LGBTI Community Research, LGBTI Community Center, or LGBTI Community Resource Center) and in literature, especially in psychology (Harper and Schneider, 2003; Mc.Ghee, 2003; Frost and Meyer, 2012; Lin and Israel, 2012). The notion of an LGBTI community is also frequently used in Honduras. Civil society organisations often refer to the entire spectrum of sexual diversity considering all its components as belonging to a single community (Arcoiris and CIPRODEH, 2009; Cattrachas et al., 2012). However, most Honduran transgender women interviewed do not feel a strong identification with other parts of the LGBTI population, especially gay men. In these women's view it is often due to prejudice against them inside the

⁷ Interview with a transgender leader, San Pedro Sula, 11 July 2012.

⁸ Interview with *Comisionado Abencio Atilio Flore Morazán, Dirección Nacional de Investigación Criminal* (National Directorate for Criminal Investigation) and *Inspectora Argentina Fuentes*, Head of Department of crimes against Life at the DNIC, Tegucigalpa, 17 July 2012.

movement, as they are regarded as poorly educated and carrying out sex work: “For most gays, transgender women are just pathetic souls; prostitutes pumped up with hormones.”⁹

*I realise that there is a lot of resentment among the transgender community against the larger LGBTI rights movement. It is often the same people who control the movement, gay men mostly, who control the funding, the programmes and the political spaces. These organisations don't give opportunities to new elements, and ideas, including those coming from the LGBTI community. But all transgender women do identify with the LGBTI community for a while at least, because we all undergo a process of gender identification that starts by being gay.*¹⁰

Most of the transgender women interviewed see the creation of independent transgender organisations as a much more suitable place to express themselves and relate to each other freely. This marks the distinction between the identification with a different sexual orientation common to LGBTI groups and the expression of a different gender identity, specific of the transgender population.

*I started in the Gay Community for Comprehensive Health of San Pedro Sula [Comunidad Gay San Pedrana para la Salud Integral]. Most of us [transgender women] started there. At the time I was a gay man with short hair and all that. But I didn't like that. I wanted to express myself as a woman. When I became a transvestite, it was clearer to me that I didn't belong. We are not part of the same community. Sometimes they reject us. Even when I was gay, I would be the first one to say: hey, there is a trans coming along, let's get out of here!*¹¹

Few transgender women interviewed see themselves as belonging to a community of transgender women; most of them are not familiar with the mere concept of community as an abstract. Responses to the question about which community or communities they think they belong vary considerably, from country, to family, to the LGBT community, to sex workers, even to a religious community: “I have always believed that I belonged to my parish [evangelist church], I was very integrated in the church activities. I underwent my sexual transformation while I was there, and I realised that the church didn't like me turning more and more feminine. Finally, the pastor came to me and asked me to take a one or two years' break to

⁹ Interview with a transgender HIV peer-educator, San Pedro Sula, 13 July 2012.

¹⁰ Interview with a transgender HIV and human rights activist, 13 July 2012.

¹¹ Interview with a transgender sex worker, San Pedro Sula, 12 July 2012.

make up my mind, hinting that I should go back to being a man.... I never came back".¹² This testimony underpins the fact that the construct of a community of LGBTI people which is largely entertained among key actors of both the human rights system and global HIV/AIDS governance is not relevant as a key element of cohesion and development of the CBOs of transgender people analysed in Honduras. It is identification and not identity what really counts in this particular context.

Human rights and HIV norm appropriation and the development of CBOs

In the absence of a common identity, owning international human rights norms has been essential in fostering the identification of transgender women with the organisations that represent them. The work of the CBOs studied for the promotion of the human rights of their members acts as a cohesive agent transcending above-mentioned tensions between identity and identification of members with the organisations which represent them. The vast majority of Honduran transgender women interviewed consider themselves as human rights activists.

Almost all transgender sex workers interviewed denounced police violence and impunity for crimes committed against transgender people. They know that they have the right to denounce these acts and to obtain justice for them. For the most part, this language has been acquired in seminars and training provided by transgender organisations, again through peers. In the particular case of Honduras, the main international norms these organisations focus their training on are indeed norms that have been incorporated by the state into the national legal framework. They refer to notion of the right to non-discrimination to accessing health, employment, education; freedom from torture and cruel, inhuman and degrading treatment by law enforcement officers, right to justice and redress.¹³ In the case of these particular norms, the CBOs analysed act as conveyers, not as translators into local realities as vernacularisers often describe the role this kind of local entities (Tarrow, 2005; Levitt and Merry, 20009). The demand is that these norms be effectively implemented by the state.

The transgender women interviewed often refer to a feeling of self-rejection, which is referred to in literature as internalised homophobia, when the transgender person assumes social rejection and prejudice against her making them her own and affecting her mental equilibrium (Davies and Neal, 1996). When discussing which of their human rights was most valuable to them, rather than the right to life, or not to be tortured or subject to cruel,

¹² Interview with a transgender sex worker, San Pedro Sula, 12 July 2012.

¹³ Interviews with transgender leaders, El Progreso and San Pedro Sula, July 2012.

inhuman or degrading treatment, which in this context would be the expected answer, the most common responses are right to employment and education, and less commonly, freedom from discrimination.

*The thing I fear the most is being killed by a client or by the police, or that another transgender sex worker attacks me on the street....*¹⁴

*The right I think we need most is the right to work. I always wonder what is going to become of me when I can no longer work as a sex worker. I graduated in IT, but I know I could never work in that as a woman. I have decided to revert back to having a masculine appearance because I know I will never, ever get a job as a transgender woman in Honduras. It would be a miracle.*¹⁵

These answers denote various degrees of internalisation of violence against the transgender community (Currie et al, 2004) to the point of considering its eradication as almost an unachievable goal even among highly empowered women.

*I know I have all the same rights as everybody else. For me the right that is less guaranteed is the right to health, because I know that if I go to a hospital as a woman, the doctors will treat me badly and will think I am HIV positive. Then, the right to education and to employment because I will never get a job as a woman. As for the right to life and not to be harassed by the police, I know that is one of the main rights, but we are so used to it, that we almost take violence against us for granted. But in fact, one of my main worries when I am putting my make-up on before going out in the night is whether a policeman will beat me or kill me.*¹⁶

There is a rationale in this counter intuitive prioritisation of international human rights norms. Lack of education and employment opportunities are at the core of transgender women being marginalised in society, and pushed to carry out sex work, where they are further marginalised and more vulnerable to violence. This acceptance of violence by most transgender women interviewed also manifests itself in organisational discourses. Most transgender organisations adopt the language used by other LGBTI organisations who qualify violence against members of the sexual minorities as hate crimes, criminal acts or attempted crimes committed against somebody motivated by their actual or perceived race, ethnicity, national origin, religion,

¹⁴ Interview with a transgender sex worker, San Pedro Sula, 12 July 2012.

¹⁵ Interview with a transgender sex worker, San Pedro Sula, 12 July 2012.

¹⁶ Interview with a transgender sex worker, San Pedro Sula, 12 July 2012.

disability or sexual orientation, or in the case of transgender women, gender identity (Gender Equity Resource Centre, 2010).

There is little debate, however, among the transgender women interviewed as to whether human rights empowerment increases or reduces their exposure to human rights violations. For most of them, knowing about their rights appears to provide a sense of security in so far as it tells them that ‘somebody should care’ about what happens to them and that they have the right to question and bring their own authorities to account for what happens to them.¹⁷ This sense of security is associated with higher self-esteem and social empowerment to confront prevailing social, cultural and religious norms.

*Knowing about my human rights, and also my obligations, has helped me to feel more respected socially. But also within my own family, who used to reject me. My parents are illiterate, and it has been hard to explain to them that as a transgender woman, I should also be considered as a human being worth of respect. I haven't been able to convince my dad, but my mum accepts me now, I even work with her in her shop dressed as a woman.*¹⁸

The limited role of appropriation of international HIV norms

The role of CBOs of transgender women in the implementation of the national response to HIV in Honduras is extremely limited as these organisations are often left out of government-led plans and strategies to tackle the epidemic. However, considering that most transgender women in Honduras are also sex workers, it is often the information on prevention of HIV transmission provided by these organisations which, at least initially, interests these women the most.

*HIV prevention work has been very important as a galvaniser of the transgender population. Most of us are sex workers and we are logically interested in protecting ourselves against HIV. That has been the entry point to activism for most of us and has improved the perception of risk among sex workers.*¹⁹

The transgender organisations analysed play a significant role in ensuring human rights-based responses to HIV. Following the same principle that peer-to-peer programmes are essential to

¹⁷ Interview with a transgender sex worker, Tegucigalpa, 17 July 2012.

¹⁸ Interview with a transgender sex worker, San Pedro Sula, 12 July 2012.

¹⁹ Interview with a transgender activist, San Pedro Sula, 11 July 2012.

reaching vulnerable populations, it is transgender organisations which provide key human rights-based HIV programmes, including rights literacy and monitoring of abuses by the police and in public health care settings. No other type of organisation or institution has the reach, legitimacy and acceptance among this population to sustain such a response. Engagement with law enforcement officers and health care providers often happens on the streets, and very ground-level access to justice programming takes place when members of CBOs of transgender women accompany physically assaulted colleagues to police stations or more friendly state services.

Since the work context of most members and volunteers in transgender HIV and human rights organisations is sex work and given the great level of violence attached to this activity, it is nearly impossible to dissociate sex work from transgender HIV and human rights activism. Human rights empowerment, understood as “the expansion of assets and capabilities of people to participate in, negotiate with, influence, control, and hold accountable institutions that affect their lives”(Narayan, 2002: 235) resonates well among this population and that has become the centre of work for the transgender CBOs analysed even in the context of HIV and AIDS.

I became an activist when my mother died from AIDS. I was 19 years old then. HIV activism helped me shape my gender identity and also to develop as an LGBTI rights defender. For me HIV and human rights activism was one and the same thing. I have seen it in my practice as an HIV prevention specialist, and how behaviour change needs to be accompanied by social change and acceptance. There has always been a combination of rejection for fear of exposure to the virus across society, including the authorities. Over the past 10 years and the development of ARVs, the quality of life of people living with HIV has improved so much that those perceptions have changed and acceptance and integration has improved.²⁰

Prominence of sex work among transgender women explains to a large degree how the ownership of international HIV norms has become a vector of further integration and internal development of the transgender organisations studied and partly as implementers of HIV programmes, which they run along with their human rights work, intertwining these interventions from both spheres, effectively contributing to the diffusion of human rights-based HIV norms. For example, HIV prevention training courses also include training on human

²⁰ Interview with a transgender HIV and human rights activist, 13 July 2012.

rights instruments and peer-to-peer HIV counselling also includes accompaniment to present complaints to police or in judicial processes.²¹

The range of HIV services provided by these organisations is extremely limited, basically reduced to condom (and on occasions, lubricant) distribution, peer-education, and some sort of moral support around HIV testing. The rest of services are in theory provided by the state. However, despite prevention of HIV being a main factor attracting transgender sex workers to transgender organisations, and a key element in the human rights empowerment that these women receive, there is some degree of discrimination against people living with HIV within the transgender population itself.

*All of us are afraid of HIV. But there is discrimination within our own transgender population against transgender people living with HIV. It was worse before but it still exists, even when everybody can see that if we look after ourselves we can live just like everybody else. But there is still stigma in the family and in society. Living with HIV still equals being promiscuous. And doing sex work, often a colleague will tell a potential client that I am HIV positive to snatch him from me. But a lot has been self-inflicted discrimination, as we didn't really know that we could live a quality life. Many of us living with HIV marginalise ourselves for that.*²²

HIV prevention services and programmes among transgender women are almost exclusively run by transgender peers with no participation or support by the state. In fact, in HIV terms, the specificities of the transgender-sex work context make it almost impossible to provide effective HIV responses from outside a population which is extremely difficult to reach.²³ As explained elsewhere in this case study, transgender women are often excluded from their families, schools and employment structures and carry out highly unregulated street sex work. This context of exclusion from public health care and the need to mobilise to provide HIV responses among the transgender population contributes to the identification of the transgender population among themselves and with the CBO representing them and has mobilised the CBOs analysed in this case study to generate their own local practice to respond to HIV outside the national HIV policies led by state institutions such as the Ministry of Health or the National AIDS Commission.

²¹ Interview with a transgender leader, San Pedro Sula, 11 July 2012.

²² Interview with a transgender woman living with HIV, San Pedro Sula, 12 July 2012.

²³ Interview with a member of the Global Fund Country Coordinating Mechanism, Tegucigalpa, 17 July, 2012.

Unable to influence state policies on human rights-based HIV norm

This case study has so far shown a high level of identification of members of the CBOs of transgender people interviewed with the organisations that represent them. This identification is at least as much due to the experiences these members encounter in terms of widespread transphobia as a sense of sharing the same identity. These organisations have fostered the embracing of both HIV and human rights norms among their members which, particularly in the case of human rights, have increased self-esteem, a feeling of safety and a sense of purpose for both CBOs and their members.

The CBOs of transgender people studied try to influence the relevant state structures in the diffusion of human rights and HIV norms that affect the population they represent. However, these organisations have been unable to make a significant impact so that the government and relevant state actors implement human rights-based HIV norms and the national HIV response in Honduras guarantees the main pillars of a human rights-based HIV response. The government does not uphold international human rights norms as applied to transgender people and it breaches a number of rights-based principles of the HIV response, in particular: equality and non-discrimination, equal access and full participation of stakeholders, community at the centre of programmes, and accountability. The lack of compliance with and enforcement of these norms reinforces Finnemore and Sikkink's call for norm diffusion theory to understand what constitutes a violation of a norm that the state has committed to implementing (Finnemore and Sikkink, 1998).

This section demonstrates that, although the Honduras government claims it has adopted a number of international human rights norms, these are not being incorporated into national practice. This is not exclusively due to a lack of capacity of the government and state actors to enforce such norms, as is for instance often the case in global health regulations with states willing to enforce comply with international regulations but lacking the technical and material resources to do so (Davies et al., 2015). In the case of Honduras, the failure of the government and other state structures to implement these norms is largely attributable to the fact that large sections of state institutions in charge of enforcing such norms, from the police to the judiciary, are unwilling to do so.

This section also describes that transgender organisations have precarious structures largely due to the little interest that HIV donors and other external proponents of human rights norms have shown to support the sustainability of these organisations. This circumstance

hinders the ability for these CBOs to leverage their position as norm implementers of human rights or HIV norms to gain agency to influence either external actors, such as international NGOs or other governments or internal non-state actors such as mainstream civil society organisations.

State appropriation of international human rights norms without implementation

Honduras has ratified all relevant international standards protecting individuals against discrimination and torture, including the International Covenant on Civil and Political Rights (ICCPR) (ratified by Honduras in 1997), the ICESCR (ratified in 1981), the CAT (accessed in 1996) and the Convention on the Elimination of All Forms of Discrimination against Women, ratified in 1983 (see Appendix 3).²⁴ Honduras has also ratified the American Convention on Human Rights, which includes provisions on the right to privacy and equal protection that have been interpreted to cover sexual orientation and gender identity (Organisation of American States, OAS, 1969). Honduras, along with other countries in the region, has acknowledged the high levels of targeted violence against the LGBTI population across Latin America, and signed four resolutions between 2008 and 2011 on human rights and sexual orientation and gender identity at the OAS, whereby governments in the region expressed their commitment to protect sexual minorities (OAS, 2011).

From a norm diffusion theory perspective, and unlike the other case studies in this thesis, Honduras has committed to international human rights norms almost directly in most cases without associating them with pre-existing, locally-acceptable norms and without needing to build congruence between these norms and underlining domestic conditions. These two processes are critical elements in the localisation of international norms described by authors as essential in norm diffusion theory (Acharya, 2004; Stevenson, 2013; Brown, 2014). However, widespread violence against transgender women in Honduras makes it clear that the application of international human rights norms through their compliance and enforcement by state structures is in serious jeopardy.

In a context of weak state structures, the incapacity of the Honduran authorities (both government and the judiciary) to enforce international norms may not mean that it unwilling to implement such norms (Davies et al., 2015). However, as far as the Honduran transgender population is concerned international norms protecting their human rights are really not being

²⁴ United Nations Treaty Collection, <https://treaties.un.org/>. Accessed on 11 June 2015.

defused to reach them. As with the other case studies although to varying degrees, the high level of non-compliance with international human rights norms by the structures of the state calls for the study of norm diffusion to go in depth as to the factors favouring or impeding the translation of these norms into national practice (Cortell and Davis, 2000; Davies et al., 2015).

The state is not only failing to protect the human rights of transgender people. State actors are actively violating these human rights directly, through the action of law enforcement officers and through widespread impunity for crimes committed against this population (HRW, 2009). The case of *the Colectivo in San Pedro Sula* is illustrative. This organisation is the largest transgender HIV and human rights organisation operating in and around San Pedro Sula. It is recognised by organs of the international human rights system (in 2009 and 2010, representatives of the organisation were chosen to speak to the OAS Assembly prior to the passing of OAS resolutions on sexual orientation and gender identity) and, as described below, also by key actors in the HIV response in the country. However, like in the case of most transgender CBOs in Honduras, the *Colectivo* is registered as a sports club, not as a human rights organisation.

This reflects increasing pressure from religious and traditional groups and growing reticence on the part of the authorities to allow the establishment of organisations defending the rights of sexual minorities. Between 2005 and 2012, no LGBTI organisation registered as a promoter of human rights.²⁵ Between 2009 and 2012, at least 15 members of the *Colectivo* were killed. This represents nearly 25% of the total membership of the organisation. In none of these cases have the perpetrators been identified. Although organisation members accompany victims of violence and human rights violations to file their cases and have lodged dozens of complaints, between 2009 and 2012 no law enforcement agent was prosecuted (Restoy and Leonardo, 2012). Senior *Colectivo* figures have received death threats, including allegedly by law enforcement officers, and as a result cannot meet in the premises of the organisation.²⁶

Police and judiciary representatives consider transgender sex workers in general as a group which poses a threat to social peace and security, as they “scandalise the population, with attitudes that are not sociably acceptable, and are often linked to the illegal drug market and the organised crime”.²⁷ However, the Honduran authorities claim that there is no targeted

²⁵ Interview with LGBTI activists, Tegucigalpa, 17 July 2012.

²⁶ Interviews with a transgender leader, San Pedro Sula, 12 July 2012.

²⁷ Interview with *Comisionado Abencio Atilio Flore Morazán, Dirección Nacional de Investigación Criminal* (National Directorate for Criminal Investigation) and *Inspectora Argentina Fuentes, Head of Department of Crimes against Life at the DNIC, Tegucigalpa, 17 July 2012.*

violence against transgender people and other sexual minorities in the country, and that the level of violence against these communities is consistent with generalised social violence.²⁸ Legislation itself and how it is interpreted by law enforcement officers and judiciary at every level of hierarchy is also revealing of how disregarded transgender women are in Honduran society, and how authorities tend to equate transgender people with sex work and crime, and regard them as a security threat. Transgender women and police authorities often refer to the Law on Police and Social Affairs (*Ley de Policía y de Convivencia Social*) as a piece of legislation regulating the interaction between both groups. This law states that the police can detain anyone who “exhibits total nudity” or “goes against modesty, proper conduct and public morals ... and disturbs the neighbours’ tranquillity with their immoral conduct”. The legal consideration of sex work in Honduras is ambiguous. Sex work is not banned explicitly, but the law establishes sanctions and detention in police stations of up to 24 hours for a several social groups considered as “vagabonds”, which includes the category of street prostitutes. This provision is being interpreted by the police, even at the highest hierarchical level, as conferring upon street sex work an illegal status.²⁹

The substantial power and discretion given to the police in provisions of the Law on Police and Social Affairs facilitates police abuse and arbitrary detentions of transgender women and serves as a tool for police officers to use when extorting money from the transgender sex workers and their clients. A common pattern of police corruption in this respect is that when a transgender sex worker enters into a potential client's car. One or several police officers will stop the car, and take out the client and sex worker separately. They will blackmail the client, threatening him with public exposure and beat the sex worker either on the street or at the police station where she is retained for up to 24 hours unless she pays a bribe. Transgender sex workers who witness acts of police brutality against another colleague or denounce violence committed by police officers are often threatened by these or other state agents, and on occasions, murdered. This pattern reflects wider social rejection and discrimination against sexual minorities the police contribute to,³⁰ but it also describes a context conducive to police violence against transgender women not always linked directly to transphobia but to corruption, lack of regulation of sex work and gender inequality (Restoy and Leonardo, 2012).

²⁸ Interview with Abogado Martín Madrid, *Superintendente de Justicia, Seguridad y Transporte de la Municipalidad de San Pedro Sula*, San Pedro Sula, 12 July 2012.

²⁹ *Ley de Policía y Convivencia Social* (Policing and Social Harmony Law), Poder Legislativo, Decreto No. 226-2001.

³⁰ Interview with a transgender leader, San Pedro Sula, 11 July 2012.

Often the police will persecute transgender sex workers suspected of being part of *maras*, or of distributing drugs on their behalf.³¹ However, transgender sex workers also point out that denouncing extortion by the *maras* at the police can be even more dangerous than complaining of police brutality, since often *maras* and police agents collaborate in extortion.³²

*I was once taken by the maras to talk to one of their commanders. They wanted to organise the girls [transgender sex workers who belong to the organisation the respondent coordinates] for them to sell the mara's drugs to their clients and in the street. I couldn't see how I would say no, these guys don't ask, they order, and if you don't comply, they know where you live and they know your family. But then a national police spokesperson who has been in some human rights workshops with us came along. At first I didn't understand what he was doing there. Now I know he is working with the maras too. When he saw me and I saw him, he had a word with the mara commander, who let me go without having to do what they wanted me to. I think the policeman got scared that I had identified him and could report him.*³³

The high level of impunity associated with this violence reported by human rights organisations and the weaknesses of the law enforcement and judiciary systems in Honduras underpin how discrimination against transgender women penetrates rule of law structures in Honduras. Out of the 51 murders of transgender women reported between 2004 and 2012 and hundreds of reported cases of attempted murder and other acts of violence against transgender women, only one person was convicted in that period.³⁴ This situation translates to the prosecution office itself, which lacks a protocol to identify transgender victims. In 2011 alone, the national police reported 20 murders of LGBTI people in Honduras, but it is impossible to ascertain who among these victims were transgender women. Disaggregated statistics and official analysis of violence against transgender women are lacking since the police do not regard transgender people as a population on its own, independent from other components of the LGBTI population. Therefore, police reports do not reflect the transgender nature of victims of crimes.³⁵ Confusion around gender identity extends also to the judiciary itself, which regards

³¹ Interviews with transgender leaders, El Progreso and San Pedro Sula respectively, July 2012.

³² Interviews with transgender leaders, El Progreso and San Pedro Sula respectively, July 2012.

³³ Interview with transgender leader, El Progreso, 13 July 2012.

³⁴ HRW, 'Honduras: Police Officer sentenced for Stabbing Transgender Sex Worker', 10 September 2010. www.hrw.org, accessed on 1 February 2011.

³⁵ Interview with *Comisionado* Abencio Atilio Flore Morazán, *Dirección Nacional de Investigación Criminal* (National Directorate for Criminal Investigation), Tegucigalpa, 17 July 2012.

transgender people as transvestites, that is, men dressed as women. According to the Office of Prosecutions, identification of the gender identity of the victims is carried out on an *ad hoc* basis at the scene of the crime, without a set identification protocol.³⁶

This context of reported impunity for crimes committed against transgender people, the lack of implementation by the state of international norms protecting this population and the widespread transphobia across large sections of the Honduran society means that CBOs of transgender women are unable to influence both state and internal actors with a role in the diffusion of international human rights norms and their full implementation for the protection of the rights of transgender women. There is also little interest among external actors such as other states and international NGOs who should be main proponents for these international norms to be effective in Honduras. The creation of the Sexual Diversity Unit within the Prosecutors Office for common crime (*Fiscalía de delitos comunes*) illustrates how far this influence could be felt.³⁷ This investigation unit tries to advance some criminal processes involving the LGBTI community through the judicial system. The unit is actually coordinated by US Federal Bureau of Intelligence (FBI) agents operating from the US Embassy in Tegucigalpa and funded by US development agency (USAID). However, the unit is focused on a few high profile cases and is not equipped to increase the protection of most transgender people in the country.³⁸

The lack of recognition of the role of CBOs in national HIV/AIDS governance

The participation of transgender organisations in the process of adoption of international HIV norms by government and other state structures in Honduras is extremely limited. Here again, CBOs of transgender women have very little participation in the implementation of HIV responses under the National Strategic Plan (NSP), which guides the national response and budget allocation (that is national practice in response to the HIV epidemic) across public entities and civil society. In this regard, transgender organisations do not receive direct organisational and financial support from the NSP budget to carry out their HIV work as they are often buried within the support provided to the population of MSM (IHAA, 2011a). This in turn makes it more difficult for these organisations to qualify to receive funds from either

³⁶ Interview with *Abogado* Germán Enamorado, *Fiscal de Derechos Humanos, Ministerio Público*, Tegucigalpa 17 July 2012.

³⁷ Interview with Vice-Minister of Justice and Human Rights, Tegucigalpa, 17 July 2012.

³⁸ Phone interview with a former member of the *Unidad de Diversidad Sexual, Procuraduría de Delitos Comunes* (Sexual Diversity Unit, Prosecutors Office for Common Crime), 19 July 2012.

internal or external donors.³⁹ Global HIV/AIDS governance agencies and international HIV donors are rapidly leaving Latin America, with Honduras being no exception, as they consider that most countries in the region have reached a middle income status that makes them ineligible to receive foreign aid.⁴⁰

However, there are some key structures operating in the country, notably the Global Fund, where CBOs of transgender women have been able to gain some space for participation (Tully, 2002). For example, in 2002, a transgender representative was appointed to participate in the Country Coordinating Mechanism (CCM) of the Global Fund in Honduras (Redlactrans, 2009). However, three years later, this seat was passed to another representative from the LGBT population, a male gay person, director of an organisation from which two transgender organisations broke away as they felt transgender people were not properly represented by the organisation.⁴¹ The CCM is supposed to guarantee the meaningful participation of affected communities in the grant making process of the Global Fund at the national level. Often, this participation is purely tokenistic as this case study shows much in line with Harman's description of CBOs' participation in HIV/AIDS Governance as their inability to translate "their involvement in the delivery at the community level...to decision-making at the national and global level" (Harman, 2012:108). Other case studies in this thesis show contexts where CBOs indeed have a more meaningful and influential participation in HIV/AIDS governance structures which depart from this statement.

The example of the CCM both illustrates the weakness of the influence of transgender organisations on the HIV response in Honduras and the general failure of institutions of global HIV/AIDS governance to understand the differences among LGBTI populations and the organisations which represent each of these sub-populations (Altman, 2005; Tamale, 2011). Therefore it would be wrong to conclude that the engagement transgender organisations have with the state and HIV/AIDS governance structures has a significant impact on the lives of transgender people in Honduras. Not only because their participation is shaped in the way that suits donors and government but mostly because this participation circumscribes itself solely to representation with little weight in strategic decisions on HIV interventions.⁴²

³⁹ Interview with a member of the Global Fund Country Coordinating Mechanism, Tegucigalpa, 17 July 2012.

⁴⁰ Interview with a member of the Global Fund Country Coordinating Mechanism, Tegucigalpa, 17 July 2012

⁴¹ Interview with a transgender leader, San Pedro Sula, 11 July 2012.

⁴² Interview with a member of the Global Fund Country Coordinating Mechanism, Tegucigalpa, 17 July 2012.

The inability of the CBOs studied in this chapter to influence either key internal and external proponents of international norms has a direct impact on the ability of these organisations to influence state actors in relation to these norms. The transgender organisations analysed are unable to contribute the boomerang effect needed for TANs, such as the Global Fund in this case, to be able to influence the state, and no other local actors among NGOs or national leadership fill this gap to connect with external proponents of international human rights norms (Keck and Sikkink, 1998). In the context of Honduras, it is evident that external actors are not fulfilling their role to pressurise the Honduras government to monitor and comply with the international norms it has committed to adopting.

As this case study has thoroughly described, the lack of influence of the CBOs of transgender women analysed has translated into minimum impact on the behaviour of law enforcement bodies and public institutions and on the access of transgender people to key interventions and services including public health care, justice and redress, education or employment.

*I am currently working as a sex worker because I lost my job as an HIV specialist after the 2009 coup-d'état. I worked between 2004 and 2008 at the Centre of Education and Prevention for Sexual Health and HIV and between 2008 and 2010 at the Pan-American Association of Social Marketing in HIV Prevention. During that time I was safe. I didn't have to carry out sex work and could afford to have a high profile both in HIV and as a human rights defender. When funding for HIV prevention programmes drained and I had to go back to sex work, which I had done for many years in the past. I felt automatically more exposed. In October 2011, I was shot at four times by two individuals who were waiting for me outside a cafe. It is the fourth attack in just over 10 years. All in all I have received nine shots. It is a miracle I'm still alive. I know the police are after me because in the 90s I witnessed policemen killing a transgender sex worker. I testified against some of them. I know I am on the list of those they want to socially cleanse. But with all my activism, I am terrified of denouncing this situation. The system hasn't failed me in terms of letting me getting prepared for work; it has failed to provide me with a sustainable job that gives me security.*⁴³

The testimony above is a good illustrator of the inability of the CBOs of transgender women studied in Honduras to influence the diffusion and implementation of human rights and human

⁴³ Interview with a transgender HIV and human rights activist, 13 July 2012.

rights-based HIV norms. These organisations are encouraged by HIV donors to carry out HIV intervention and human rights work. This empowerment encourages these women to be vocal in their attempts to influence the state exposing them to violence and harassment by the state itself. However, no provisions are made among HIV donors as to the safety of these people and to support their participation in decision making fora to increase their agency. When funding dries up, there is no provision for the sustainability of these organisations and because donors have not invested in the reinforcement of their financial and organisational structures, most of their personnel return to sex work and to work for the organisation on a voluntary basis, but with a higher degree of exposure to human rights violations than before.⁴⁴

Conclusion

This case study presents evidence that by embracing international human rights norms and principles, the CBOs of transgender women studied in Honduras contribute greatly to the sense of identification of CBO members with each other and with the organisation representing them, and to the self-esteem of CBO members. All case studies describe this empowerment as contributing to sexual behavioural changes to better respond to HIV among the populations studied. The transgender organisations analysed in this case study appropriate HIV norms too, using HIV prevention services as a vehicle to attracting new members and the funding they receive serves to reinforce their structures and promote human rights literacy and programmes among their members. This simultaneous assimilation of both international human rights and HIV norms means that, even with precarious structures, the CBOs studied contribute to the diffusion of international human rights-based HIV norms through their interventions, constituting local practice which contributes to the domestic practice in response of Honduras to the HIV/AIDS epidemic among transgender people, even when the state itself is not contributing to it. In norm diffusion terms, this is evidence that in the particular context of global HIV/AIDS governance system, actors other than states may play a role in owning and implementing international norms (Reza-Paul et al., 2008; Seckinelgin 2008; Harman, 2012).

The ownership of international human rights norms by the CBOs of transgender people studied plays an important role in the empowerment of this population and the development of these organisations, prompting them to try to influence human rights norm implementation (enforcement of and compliance with) and intervene in the diffusion of HIV norms carried out by state structures (such as the Ministry of Health or the National AIDS Commission) or under

⁴⁴ Interview with a transgender HIV and human rights activist, 13 July 2012.

its coordination (like the CCM) as well. However, CBOs of transgender women in Honduras are unable to influence these and other relevant state structures (such as the police or the judiciary) to comply with and enforce human rights-based responses to HIV. From this point of view, this case study represents a one-off situation seemingly contradicting a central claim of this thesis as to the influence CBOs can indeed have on institutions representing the state regarding the enforcement international norms.

The case study identifies two key descriptors of such inability. Firstly, CBOs of transgender women are not fully integrated in the state-led national HIV response in their country. This is due to a vicious circle of not having solid structures with the skills and governance needed to qualified as implementers, which in turn leads means that they cannot access the necessary resources to be able to play their part in the response and leverage that participation to influence the state regarding human rights and HIV norms. Secondly, and as a direct result of the previous circumstance, the CBOs of transgender women analysed are unable to reach out to either key external actors (donors, organs of global HIV/AIDS governance) or internal actors (larger civil society, public opinion, etc...) with the necessary agency to influence the state.

This case study makes an additional contribution to vernacularisation theory. The CBOs of transgender women studied in this chapter embrace international human rights and HIV norms without much translation into the local context. This is consistent throughout the case studies and contrasts with the notion in literature of CBOs as vernacularisers (Tarrow, 2005; Levitt and Merry, 20009) as they behave more like conveyers of international norms to the populations they represent. As in the other case studies, transgender people see in these norms a way of confronting a highly stigmatising social environment. This contrast is less marked in Honduras compared to the following chapters on CBOs of drug users in Ukraine and LGBTI organisations in Uganda. Unlike in these two countries, Honduras is a state party to most international human rights legal standards. However, the widespread impunity for violence and human rights violations committed against transgender women shows the failure of the state to incorporate into national practice international norms for the protection of sexual minorities it claims to have committed to.

5. APPROPRIATION AND RESISTANCE: ORGANISATIONS OF PEOPLE WHO USE DRUGS IN UKRAINE

Introduction

The CBOs of people who use drugs in Ukraine analysed in this case study play a more significant role in the diffusion of international norms than the organisations of transgender women in Honduras described in the previous chapter. In addition to international human rights norms, specific international human rights-based HIV interventions for drug users (harm reduction programme principles and guidelines) play a significant role in the development of the CBOs of drug users studied, since along with social rejection and criminalisation, the shared medical condition around drug use is critical to the cohesion, services and strategies of the CBOs representing them (Benny et al., 1996; Friedman et al., 2012). These CBOs have generated their own local practice based on international human rights-based HIV norms carrying out a vast portion of the domestic response to HIV among drug users in the absence of state-run services for this population and widespread persecution of drug users.

This case study also provides evidence that the CBOs of drug users analysed are able to, albeit partially, influence state institutions on the diffusion of human rights related norms in Ukraine. Unlike the CBOs studied in Honduras, these organisations of people who use drugs in Ukraine play a recognised role in the delivery of harm reduction programmes which they leverage to influence international donors and other external actors as well as the Ministry of Health, which recognises the CBOs' role in the national HIV response among drug users. However, these organisations are unable to influence the rejection by the Ministry of Interior and other relevant state authorities of international human rights norms protecting people who use drugs. This fact underlines the three main contributions this case study makes to norm diffusion theory.

Firstly, the case study questions the consideration of the state as a single structure as is often the case in norm diffusion theory (Nadelmann, 1990; Cortell and Davis, 2000; Stoeva, 2010). The state is represented by different actors in various norm diffusion processes. This explains that a single country can indeed simultaneously commit to two or more opposing or contradicting international norms. Through its health authorities, Ukraine has accepted the introduction of international human rights-based HIV norms based on harm reduction interventions in the response to HIV among drug users. At the same time, state security

authorities have represented Ukraine in its resolute embracing of international drug policy norms conducive to the persecution of drug users. This circumstance makes the study of the various behaviours of relevant actors and institutions representing the state essential in norm diffusion theory.

Secondly, the coexistence of opposing international norms Ukraine has committed to implement represents another argument as to the importance of the phase of implementation of international norms in the study of their diffusion, providing an alternative pathway for states to reject or modify international norms, other than the congruence building model (Acharya, 2004; Stevenson, 2013). Instead of *glocalising* international norms infusing them with “local customs” (Brown, 2014: 878), the Ukrainian authorities appropriate opposing international norms simultaneously (drug policy on the one hand, human rights on the other) with the human rights ones just not being implemented. This in practice leads to a *disappropriation* of one international norm by an opposing international norm overturning the former, a variation of Acharya’s description of norm displacement as the failure of an international norm to overturn an existing local norm (Acharya, 2004).

Finally, if a state has committed to two or more opposing norms, it is imperative to know which of these norms prevails to the point of being introduced in national practice and the factors behind that occurrence. This chapter contributes to the study of norm hierarchies as it describes the tension that the coexistence of harm reduction and drug policy norms generates, underpinning the fact that norms often compete with other norms (Meyer et al., 1997; Finnemore and Sikkink, 1998) and have various degrees of domestic salience (Cortell and Davis, 2000). The response as to which international norms prevail over the others in this case study is demonstrated by the inability of CBOs of people who use drugs to reduce the highly restrictive human rights environment drug users endure and which extends to the regular crackdown of harm reduction services as contrary to drug policy norms and practices. The priority given to these norms reveals that it is the state security structures which prevail over public health structures when it comes to implementation of international norms in Ukraine.

Context: a concentrated epidemic of HIV among people who use drugs

The HIV epidemic is spreading in Eastern Europe faster than in any other region in the world. Ukraine’s HIV infection rate among people aged 15 and above is 1.3%, the most severe in Europe, with an estimated 360,000 Ukrainian people living with HIV. The HIV epidemic in Ukraine

is mainly driven by drug use. The HIV prevalence rate among the drug injecting population is 22.9%, one of the highest in the world (USAID, 2010). However, drug users make up only 7.5% of all those receiving antiretroviral treatment (Ministry of Health of Ukraine, 2010), in spite of representing around 60% of all people living with HIV in Ukraine (Nieburg and Carty, 2012).

Like in many other countries, a person who injects drugs and is unable, or simply unwilling to stop, needs to be able to inject regularly in safety, avoiding overdose or injecting unsafe substances, minimising the risk of being infected by HIV and other communicable diseases or, in the case of people living with HIV, reducing the risk of infecting other people who use drugs through sharing equipment, or sexual partners. A person who uses drugs also needs to maintain their livelihood and feel integrated in their families and the wider community, beyond their inner circle of fellow drug users (IHAA, 2010). For most drug users in Ukraine, however, the reality is very different, even when they count on the support of their family. Drug use is criminalised and carries with it widespread stigma and discrimination from across society, including the state, against people who use drugs.

The most established practices of reducing HIV transmission among people who inject drugs are harm reduction interventions, which require a human rights-based approach to drug use with the consideration of drug users as patients rather than threats to security and takes place within communities of people who use drugs themselves. The harm reduction package comprises of needle and syringe exchange programmes, which consist of providing sterile injecting equipment to people who use drugs in exchange for used equipment to reduce the risk of transmission between people who share equipment; drug substitution maintenance treatment (SMT), normally through the controlled administration of methadone, buprenorphine, or other synthetic opioids (DPA, 2006), which reduces the risks associated with the uncontrolled use of heroin and other illegal opioids, including among others, overdose (Mattick et al, 2003); peer education amongst drug users; and efforts to improve the access of HIV positive people who use drugs to services such as HIV testing and treatment, sexual and reproductive health services, tuberculosis services and supervised injecting centres.

Harm reduction approaches are largely believed to have a positive impact on public health. For instance, needle and syringe programmes have contributed to a dramatic decrease in HIV transmission among people who use drugs, by up to 33-42% in some settings (WHO, 2004; Wodak and Cooney, 2006); and Opioids Substitution Therapy (OST) improves access and adherence to antiretroviral treatment and reduces mortality (Spire et al, 2007). Others, such as

supervised injection sites, are controversial as to their effectiveness (WHO, UNODC and UNAIDS, 2009).

Appropriation of international norms among people who use drugs

The CBOs of people who use drugs in Ukraine analysed in this case study have a significantly higher role in the diffusion of international norms than the CBOs of transgender women in Honduras described in the previous chapter. Much like in the case of Honduras, ownership of international norms is a critical element in the identification of people who use drugs in Ukraine with each other and with the organisations representing them analysed in this chapter. In this case, however, along with human rights norms, international HIV norms for drug users (harm reduction programme principles and guidelines) play a significant role too, since along with social rejection and criminalisation, the shared medical condition associated with drug use is critical in the cohesion, services and strategies of the CBOs analysed. This identification is noted in literature and highlights the role that global HIV/AIDS governance has played in recognising and supporting organisations representing populations with a strong identification based on health-related conditions (Benny et al., 1996; Friedman et al., 2012). This role conditions the kinds of human rights this population claims, where the right to health (in this case to therapies in substitution of heroin addiction) is much more prominent than for instance, in the case of organisations of transgender women in Honduras.⁴⁵

This case study focuses mostly on ENEY (*Drug Users Anonymous*), one of the most relevant CBOs of people who use drugs in Ukraine and other smaller organisations of drug users. Most of the people interviewed belong to ENEY. The organisation was created in the 2000s originally as a drug addiction treatment support group (Narcotic Anonymous), working in a similar way to Alcoholics Anonymous. Although ENEY still provides services for those trying to break their drug use habit, it now focuses on harm reduction programmes for ongoing drug users and on HIV services. The majority of the personnel is formed of volunteers who are drug users living with HIV, providing peer-to-peer harm reduction services such as distributing clean needles in exchange of used ones. ENEY has social clubs and support groups, as well as a mobile testing laboratory for HIV, Hepatitis C and related diseases. It currently supports around 10,000 drug users. Although ENEY's management and governance structures are still precarious and rely heavily on volunteers, they are strong enough to be eligible to receive funds from the Global Fund, one of the biggest proponents of harm reduction programmes worldwide and

⁴⁵ Interview with a representative of the All-Ukrainian Network of People Living with HIV, Kiev, 19 November 2011.

from whom it receives most of its funding.⁴⁶ This support from a significant actor in global HIV/AIDS governance contrasts significantly with the difficulties CBOs of transgender organisations in Honduras experience trying to obtain funding.

As among the transgender women interviewed for the case study on Honduras, the first main feature in the identification of drug users interviewed in Ukraine with the CBOs which represent them is social rejection.⁴⁷ People who use drugs in Ukraine, as in many other parts of the world, are highly stigmatised and discriminated against (Maksymenko, 2010; Burki, 2011). This stigmatisation often throws people who inject drugs out of the education system and out of social spaces where they can have access to essential information about safe drug injecting and safe sexual practices, vital to prevent the spread of HIV. Even if such information was widespread, social discrimination means that most Ukrainian people who use drugs would not turn up on a regular basis to receive health services for fear of being spotted or exposed by neighbours or others.⁴⁸ Certainly, not all Ukrainians who use drugs, either injecting or otherwise, feel the same degree of social rejection. Some have strong family support and are relatively well integrated within wider society. However, they all are placed by the state at the margins of legality (Maksymenko, 2010).

*ENEY started as a self-help group for those who wanted to quit drugs, but more as a matter of survival and resistance to police harassment...We live the same things and I relate to other members, but I don't think we have the same identity, I am my own man, I have my family and friends who have nothing to do with drugs.*⁴⁹

Criminalisation of drug use and alleged human rights violations by law enforcement officials are other critical elements in the building of the distinct population of people who use drugs conferring it with a clandestine nature, with a shared sense of being outside the official structures laid down by the state. Cohesion among CBOs of people affected by HIV, as described in the case of transgender organisations in the previous chapter, may be reinforced with the common perception of their members as identifying with each other and the CBOs representing them not so much through a shared identity, but rather through a shared health condition. This kind of identification may also shape the negative social perception in Ukraine towards

⁴⁶ Interview with a founding member of ENEY, Kiev, 16 November 2011.

⁴⁷ Interview with a founding member of ENEY, Kiev, 16 November 2011.

⁴⁸ Interview with a representative of the All-Ukrainian Network of People Living with HIV, Kiev, 19 November 2011.

⁴⁹ Interview with an ENEY activist, Kiev, 19 October 2011.

people who use drugs. Social representations of ‘deviance’ or ‘illness’ can affect the individual’s self-confidence thus increasing their vulnerability (Howarth, 2002). Negatively evaluated social identification, as in the case of people who use drugs, can therefore perpetuate marginalisation (Goffman, 1968).

This background explains the embracing by the people who use drugs interviewed of international human rights norms stating the dignity of individuals and the principle of non-discrimination in accessing the right to health. This demand is embedded in most of the programmes the CBOs of drug users studied provide and the advocacy they carry out, and sits alongside demands that law enforcement officers stop arbitrary detention, cruel, inhuman or degrading treatment of drug users, as well as upholding the right to privacy; all of which are enshrined in international human rights standards ratified by Ukraine.⁵⁰ The organisations of people who use drugs analysed in this chapter organise to claim their rights and reach out to NGOs, IGOs and other organisations and networks mostly outside Ukraine. Support among mainstream human rights organisations within Ukraine is more limited.

*We know that what we are claiming are fundamental rights. But not everybody thinks the same. There are so many so called human rights organisations that say: you are drug addicts, how can you expect the same rights as everybody else?*⁵¹

Most members of the CBOs of people who use drugs interviewed consider their participation in harm reduction programmes and peer-to-peer solidarity networks as human rights work, and themselves as human rights activists fighting for the rights of people who use drugs.

*Everybody here is a human rights fighter. How many activists do you know that would go out on the streets, and strike deals with the mafia or the police to make sure that clean needles were distributed? It might not look pretty, but we are out there risking our lives for the rights of other people all the time.*⁵²

Without carrying out campaigns or lobbying the government, the CBO members interviewed see themselves as a community that is claiming their human rights and getting results for themselves, and not thanks to others campaigning on their behalf. For instance, it is mostly

⁵⁰ Including the ICCPR (ratified in 1973); the CAT (ratified in 1987); and the Convention for the Protection of Human Rights and Fundamental Freedoms (ratified in 1997). Source: United Nations Treaty Collection, <https://treaties.un.org/>. Accessed on 1 June 2015.

⁵¹ Interview with a peer educator, Kiev, 17 October 2011.

⁵² Interview with a peer educator, Kiev, 17 October 2011.

down to the mobilisation of people who use drugs that harm reduction programmes are not illegal in Ukraine (OSI, 2008).

*When I first came here and was offered the drugs [substitution therapy], I thought they were drug dealers or something, even if I was coming to a clinic. This is Ukraine, you know? I didn't believe what they were doing for us wasn't illegal.*⁵³

For ENEY, the legality of harm reduction programmes in Ukraine is one of the most clear descriptors of the impact of CBOs of people who use drugs claiming their human rights (the right to health in this case) since none other civil society organisation in Ukraine, including human rights organisations, have paid much attention to this demand.⁵⁴

CBOs and the diffusion of human rights-based HIV norms in Ukraine

The role that CBOs of people who use drugs in Ukraine play in the implementation of the HIV response is recognised by key actors in national HIV/AIDS governance. The CBOs studied in this chapter have leveraged this role to influence parts of the state and international donors and other external proponents of human rights-based HIV norms to ensure the diffusion some of these norms, in particular, harm reduction programmes. The analysis of this limited influence challenges the assumption that the agency of CBOs participating in the HIV response is undermined by bureaucracy and donors' imperatives (Marsland, 2012) and by weak networks of organisations and solidarity (Beckman and Nujra, 2010; Boesten, 2011). The case study shows that the CBOs studied use the recognition of their role in the implementation of international norms particularly among outsider proponents of international norms to both generate robust local practice to implement such norms and to influence the Ministry of Health and other state actors. This recognition was largely lacking in the case of the CBOs of transgender women studied in Honduras.

Ukrainian CBOs have gained considerable influence among international NGOs and international donors of HIV and harm reduction programmes which champion the provision of the peer-to-peer services these CBOs offer, and the consideration of human rights-based interventions to mitigate the use of drugs treating drug users from a health care perspective and not as a threat to security. Unlike the CBOs studied in Honduras, the CBOs analysed in Ukraine connect with outsider proponents of human rights-based HIV norms such as harm

⁵³ Interview with a person who uses drugs, Kiev, 19 October 2011.

⁵⁴ Interview with an ENEY activist, Kiev, 19 October 2011.

reduction programmes to ensure their place in the implementation of such programmes to gain strength and agency to influence key actors in the diffusion of harm reduction norms, thus playing a part in the spiral model described by Risse and Sikkink. However, these CBOs make that connection at the moment of norm implementation, not at the earlier stage when international socialisation of norms takes place which is when, according to Risse and Sikkink, external proponents are most likely to influence norm diffusion (Risse and Sikkink, 1999).

Although harm reduction is an approach to public health, the links between harm reduction and human rights have been thoroughly highlighted in literature. Harm reduction is often defined as policies and programmes which attempt primarily to reduce the adverse health, social and economic consequences of mood altering substances to individual drug users, their families and their communities (Elliot and Csete, 2005). Harm reduction approaches clearly implement international human rights-based HIV norms as they fill the criteria outlined by Clayton et al. One central element of most harm reduction programmes is the empowerment and involvement of CBOs of people who use drugs to provide HIV services for their members and the wider population of people who use drugs for the full enjoyment of their human rights (OSI et al, 2008). This follows the principle of greater involvement of people living with HIV, to which Ukraine among other governments committed when signing the Political Declaration on HIV and AIDS (UNGA, 2011) and is consistent with a number of international human rights instruments, such as the ICCPR, which recognises the right to take part in the conduct of public affairs (ICCPR, Article: 55) without discrimination based on 'other status', which should include health and HIV status or drug use (OSI et al., 2008). Harm reduction approaches also involve human rights programmes such as advocacy for the rights of drug users and sensitisation of law enforcement officers and public health care workers (Clayton et al., 2014).

Although both social rejection and the perceived repression by the state represent common experiences among most drug users in Ukraine, these factors do not suffice to explain the proliferation of CBOs of people who use drugs. A major contributor to the creation of such organisations is the need for safe injecting practices and access to methods to prevent the transmission of HIV and other communicable diseases. This initial need for services eventually placed CBOs of people who use drugs at the centre of the diffusion of HIV norms among people who use drugs in Ukraine.⁵⁵ This is due to the fact that in Ukraine international donors pro-

⁵⁵ Interview with an ENEY representative, Kiev, 18 October 2011

vide funding for HIV responses among drug users which are directly implemented by NGOs and CBOs without national norm takers, in particular, the Ministry of Health and related state-run institutions, taking any active role in the process.

CBOs of people who use drugs in Ukraine such as ENEY are often loose organisations where members themselves decide strategies and manage the organisations. These structures are often primarily organised as providers of harm reduction and HIV prevention programmes, combining this work with human rights-related activities, where a vast proportion of their work is mostly focused on supporting each other to cope with of social rejection, state-sponsored violence and harassment. The bottom line quest of the community of people who inject drugs, generated around harm reduction and prevention of HIV, is the acceptance by wider society that living with drugs without posing a threat to the security of wider society is possible and that therefore people who use drugs should be accepted and protected on an equal footing as any other citizen.

*When we get this right [substitution therapy and harm reduction programmes], we get drug users to function in society. I am a living proof of it. We want to show that even if we take drugs we can be useful to society and not pose a threat to anybody.*⁵⁶

The CBOs of people who use drugs analysed in this case study provide three main types of services. Firstly, these organisations are often the only point of contact for people who use drugs; offering solidarity networks, support groups to deal with social rejection, drug dependency and livelihoods, and at a later stage, to organise to claim their rights. Secondly, these CBOs offer behavioural interventions (designed to reduce individual risks associated with drug injection and risky sexual practices). Thirdly, these organisations provide biomedical interventions through the provision of SMT and other harm reduction interventions and, in the case of drug users living with HIV, the provision of antiretroviral treatment. All these interventions have a strong participation of drug users through peer support and are provided in combination to cover the needs of drug users holistically.⁵⁷ ENEY's office in Kiev is a good example of the communitarian nature of the outreach work among people who use drugs. More of a social club than a formal office, it has a bar, a TV with videos and plenty of sitting room.⁵⁸

⁵⁶ Interview with an ENEY representative, Kiev, 18 October 2011.

⁵⁷ Interviews with a representative of All Ukrainian Network of People living with HIV and with a founding member of ENEY, Ukraine, Kiev, 18 and 16 November 2011.

⁵⁸ Interviews at ENEY offices, Kiev, 17 November 2011.

Adherence to SMT is virtually 100% in this clinic and there is not much problem in convincing drug users to take up our service. To the contrary, we have capacity for around 80 clients but we are serving 95. There are over 100 on the waiting list. We are in contact with the families and follow up with clients to make sure they stick to the programme. Clients change their lifestyle thanks to the programme. They don't have to resort to crime to get hold of illicit drugs, their lives are more organised around the clinic. They have their doses regularly and in an orderly fashion. There are no problems with overdose. They can plan pregnancies, reduce risks to HIV and STIs, they have a healthier diet, their self-esteem is higher and most of them have a better social life, including the family and other people who don't use drugs.⁵⁹

The influence of these CBOs in the diffusion of international HIV norms in Ukraine is deep, since given the criminalisation of drug use and the high levels of stigma and discrimination associated with it, any harm reduction programme in Ukraine can only be effective if drug users come together as CBOs to deliver essential activities, such as peer-to-peer counselling. From that point of view, the existence of CBOs where people who use drugs can go to safely is essential in the response to HIV among drug users in Ukraine.

For us, it is now clear that it is not impossible to live with drugs. I have tried to quit more than 24 times, and couldn't make it. So what do you do with me? Do you leave me on the street? I now come to the [CBO] centre, have my dose, I'm safe, I'm ok, I don't need to go back to heroin and make a mess of my life again.⁶⁰

This essential participation in the effective implementation of international HIV norms is underpinned by the fact that these CBOs in reality interact with official state structures, sometimes in total confrontation to them, others in some sort of collaboration. For parts of the Ukrainian state, organisations of drug users are interlocutors, for other outlawed groups placing themselves at the margins of society. In most cases, these CBOs place themselves between the state and the individual, creating a layer of interaction between the two that did not exist before they were created and which does not correspond to any traditional state-created structure.

The most critical and controversial set of interventions as regards to drug use in Ukraine are behavioural and biomedical interventions, which often take place simultaneously.

⁵⁹ Interview with a medical doctor, SMT clinic, Kiev, 19 October 2011.

⁶⁰ Interview with a drug user, SMT centre, Kiev, 19 October 2011.

Behavioural interventions aim at sensitising drug users to adopt injecting and sexual practices that minimise their risk to HIV and other diseases, including, for instance, using new injecting equipment all the time and avoiding sharing it, and condom use. Key biomedical interventions include medication-assisted treatment, including the provision of OST in clinics, and HIV voluntary counselling and testing often in mobile clinics, which are parked in neighbourhoods where drug dealing takes place. Unlike in the Russian Federation for instance, people who inject drugs in Ukraine have the possibility of accessing the biomedical aspects of harm reduction programmes.

In this respect, although Ukraine has committed to implementing international harm reduction programmes and has committed to enforcing and complying with international human rights-based HIV/AIDS governance norms as regards to drug users, the coverage of such programmes is low. Like almost all other states in the world, Ukraine reports periodically on its progress fighting HIV through a monitoring system called UNGASS reporting. In its 2010 UNGASS report, which covers progress in 2008 and 2009, the Ukrainian government states “substitution maintenance therapy using methadone and buprenorphine [OST] was received by as many as 5,078 patients at 102 health care facilities in 26 regions of Ukraine. Thus, over two years the number of drug dependant people who gained access to OST programmes increased nine times, making OST scale up one of the most successful achievements in the national response to HIV/AIDS”. However, the percentage of people covered with prevention programmes in 2009 was only 32% of injecting drug users (Ministry of Health of Ukraine, 2010).

SMT programmes are included in the National Programme for HIV Prevention, Treatment, Care and Support for 2009-2013, repository of national practice in response to HIV in Ukraine, approved by law in February 2009.⁶¹ The plan foresees the provision of methadone to 20,000 people by the end of 2013.⁶² On 15 January 2011, the Ukrainian President approved a new AIDS Law, which specifically spells out the provision of needles and syringes as well as OST to help tackle the HIV epidemic among people who inject drugs. Several directives by the Ministry of Health regulate the introduction of SMT and methadone is included in the List of Essential Medicines approved by the ministry in 2008. This apparent support by the Ukrainian authorities for harm reduction programmes for people who inject drugs has the caveat that at present all HIV prevention and harm reduction services for people who use drugs are exclu-

⁶¹ Law No 1026-VI, 19/02/2009.

⁶² Law No 1026-VI, 19/02/2009.

sively provided by non-governmental organisations with foreign funding (mostly from the Global Fund and PEPFAR).⁶³

*Practically, all harm reduction programmes in Ukraine are run thanks to peer-to-peer activities run by ENEY and other organisations of drug users. If a doctor, or a government official comes close to drug users, they will never trust them, the programme would never work.*⁶⁴

*The provision of harm reduction programmes in Ukraine is tolerated rather than encouraged by the authorities. They know these programmes are effective, but they don't like it that drug users are supported this way. We support the groups [CBOs of people who use drugs] because they are the only ones that can provide the services, but it is a very risky investment, they could be shut down any time.*⁶⁵

Nieburg and Carty stressed in 2012 that OST had never been part of narcological services provided by the Ukrainian public healthcare service (Nieburg and Carty, 2012). Authorities themselves confirm that the healthcare service does not provide any direct harm reduction service to injecting drug users (Ministry of Health of Ukraine, 2010). This state of affairs means that in reality, the national provision of harm reduction programmes in Ukraine is effectively implemented by CBOs of people who use drugs themselves with support from external actors (international NGOs and funding from international donors), without any major part being played by the Ukrainian Ministry of Health and other state structures.⁶⁶ In norm diffusion terms it means that the CBOs of drug users in Ukraine analysed in the case study generate their own local practice of human rights-based HIV norms with the support of international donors. This practice is recognised by the health authorities as contributing to the national response to HIV among drug users. However, as discussed later on in this chapter, these CBOs often need to bypass national drug policies contrary to the human rights-based norms underpinning harm reduction programmes to be able to provide their significant contribution to domestic practice of human rights-based HIV norms among drug users.

⁶³ Ukraine is the largest recipient of funds from the Global Fund in Eastern Europe for AIDS related programmes (Global Fund. Grant Portfolio information: <http://www.theinternationalfund.org/programs/country/?lang=en&countryID=UKR>).

⁶⁴ Interview with Ministry of Health representative, Kiev, 15 November 2011.

⁶⁵ Interview with a UK DFID representative in Kiev, 19 October 2011.

⁶⁶ Interviews with Ukrainian NGO representatives, Kiev, 15 November 2011.

Unable to infuse human rights norms into government policies

Despite the apparent commitment of the health authorities to harm reduction HIV programming and their acceptance of CBOs as key in the diffusion of HIV norms among people who use drugs, international human rights organisation claim that these authorities fall short of guaranteeing the implementation of human rights norms with regard to people who use drugs outside the context of HIV (HRW, 2011). The legal and law enforcement environment in support of harm reduction contradicts other legislation and policy practices that underpin the imperatives of drug control (see next section) exposing lack of coherence in government policies and highlights the inability of CBOs, NGOs and other promoters of human rights to influence the implementation (compliance with and enforcement by the state) of human rights norms among people who use drugs.

Ukraine maintains strict legislation on combating illicit drug circulation. For example, Articles 309 and 303 of the Criminal Code of Ukraine; Article 185 of the Administrative Code of Ukraine, the Law of Ukraine “On Response to Illicit Drug Circulation...” and the Law “On the Militia” all confer criminal responsibility to the possession of small amounts of illegal drugs. This deters people who use drugs from approaching any health or social services for fear of being reported or detained by the police (Maksymenko, 2010). Pre-trial detention is another barrier to treatment for people who use drugs as it impedes their access to substitution therapy and other harm reduction programmes. Pre-trial detainees in Ukraine often await trial for over a year (Wolfe, 2007).

In this repressive legal context, the mere provision by CBO members of harm reduction services may put harm reduction practitioners at the edge of legality, as it can be seen as nurturing an illegal activity while in fact they provide officially sanctioned public health interventions. Although clinics and social centres such as ENEY’s distribute clean needles in exchange for old, the bulk of the intervention takes place on the street or even in houses of drug users and dealers. Harm reduction organisation volunteers park their cars, stuffed with new and returned syringes at the very spot where drug dealers distribute drugs. There is where drug users exchange their syringes and get condoms and advice from volunteers. From a distance, it is impossible to distinguish whether drug dealing or HIV prevention work is taking place.

It is only drug users who can convince other drug users of the need to get tested and undertake harm reduction programmes. We run a network of peer-to-peer counselling and some of those who are under harm reduction become counsellors. They just need to stick

*to their work. Being off drugs and on SMT is not a requisite provided that they do their job. We give them commissions for each new client they serve.*⁶⁷

*Some drug dealers are also part of our counsellors. In fact that is one of the best ways of ensuring that drug users take precautions. We give them syringes and condoms in their own flats and they distribute among their own customers. It is impossible for government bodies to do this work as their function is to fight drug dealing and also because they would never be trusted by the dealers and drug users.*⁶⁸

Any drug user approaching the syringe exchange car could potentially be arrested, as could the volunteers as the residual drugs in the returned syringes put together could amount to possession of drugs with intent to deal with them.⁶⁹ According to volunteers, the police are aware of what is going on and in some spots and depending on the neighbourhood they may or may not ask for a 'commission'. However, the whole operation is run fast and clandestinely for fear of changes in police personnel in the area and to avoid raising suspicion from the neighbours.

*Let me tell you a little secret, the police know all the drug dealers in Kiev. So there is really not much problem if we stand near a flat where drugs are sold distributing syringes and talking about HIV prevention. The police have their yearly targets, they arrest just the number of drug dealers necessary to reach their targets, with the rest it's a matter of extortion. Police salaries are very low in Ukraine, you know?*⁷⁰

Civil society organisations have publicly denounced numerous instances of criminal prosecution, harassment and intimidation by law enforcement officers not only of people who use drugs enrolled in SMT programmes but also of medical and other health, social and outreach personnel involved in the provision of such programmes. An illustrative example of the tension between law enforcement and the provision of harm reduction programmes is the case of Dr Illya Podolyan, a physician who provided SMT for people who use drugs.⁷¹ He was detained in May 2010 by the Odessa police and charged with allegedly committing over 40 crimes related to drugs trafficking. He was remanded in prison for over five months in spite of poor health. He was released in September 2010 and finally acquitted of all counts. A few months later, in

⁶⁷ Interview with a representative of an organisation of drug users, Kiev, 18 November 2011.

⁶⁸ Interview with a drug user, volunteer in Drug User Organisation, Kiev, 18 November 2011.

⁶⁹ Interviews at a street syringe exchange programme, outskirts of Kiev, 17 November 2011.

⁷⁰ Interview with a drug user, volunteer in Drug User Organisation, Kiev, 18 November 2011.

⁷¹ Phone interview with Dr Podolyan, Kiev, 13 December 2011.

January 2011, the Ministry of Interior's drug enforcement department ordered comprehensive inspections of harm reduction programmes across the country.

Hundreds of patients receiving SMT, and NGOs and CBOs which provided this therapy in Ukraine at the time, faced harassment and abuse from state authorities implementing the Ministry of Interior's drug enforcement department's policies. Civil society organisations claimed that SMT was withheld from patients unless they provided information on their health and HIV status for a 'voluntary survey'. CBOs and human rights NGOs expressed concerns that these actions breached privacy laws as collecting individuals' personal data including their HIV status was a violation of their human right to privacy. Documents were reportedly confiscated from charity organisations; in some cities programmes for drug users stopped for a few days.⁷²

The UN High Commissioner for Human Rights, the UN Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health (Special Rapporteur on Health) and the UN Special Rapporteur on Torture and other cruel, inhuman or degrading treatment or punishment (Special Rapporteur on Torture) have all raised concerns about the failure of states to meet their human rights obligations *vis-à-vis* people who use drugs and the negative consequences of this failure on both the individual health of drug users and broader public health concerns.⁷³ In 2007, the Committee on Economic Social and Cultural Rights recommended in its Concluding Observations on Ukraine that the state party "make drug substitution [maintenance] therapy and other HIV prevention services more accessible for drug users".⁷⁴

Drug policy and rights-based HIV norms: clash and hierarchy

This case study has described the difficulties that the state of Ukraine has in effectively implementing (enforcing and complying with) the international human rights-based HIV norms (harm reduction norms) that it has committed to adopting, showing stark contradictions in government policies, often between health and law enforcement public structures. Much of this tension is explained by the interference of drug policy, which can be defined in norm diffu-

⁷² IHAA, Ukraine campaign Action, January 2011. www.whatspreventingprevention.org accessed on 29 February 2011.

⁷³ See for instance, Statement by the UN High Commissioner for Human Rights at the *High Level Review of the Political Declaration and Plan of Action on International Cooperation towards an Integrated and Balanced Strategy to Counter the World Drug Problem*, Vienna, 13-14 March 2014; Special Rapporteur on Health's report on drug control to the UN General Assembly, A/65/255, 6 August 2010; and the Special Rapporteur on Torture's report on certain forms of abuses in health-care settings to the Human Rights Council, A/HRC/22/53, 1 February 2013.

⁷⁴ Concluding observations of the Committee on Economic, Social and Cultural Rights to Ukraine, 2007 paras 28, 51.

sion theory as a norm diffusion system of its own (Krook and True, 2010). The existence of international drug policy norms which oppose international human rights-based HIV norms such as harm reduction norms evidences the consideration in norm diffusion literature that norms often compete with other norms in complex normative spaces (Meyer et al., 1997; Finnemore and Sikkink, 1998).

The fact that Ukraine has simultaneously committed to adopting opposing norms from the drug policy governance on one hand, and global HIV/AIDS governance on the other, provides an alternative pathway to explain the failure of a state to implement a particular international norm other than through its declared opposition to it. Instead of openly contesting human rights-based responses to HIV among drug users who treat this population as patients and not as a security threat, the Ukrainian authorities appropriate simultaneously international drug policy norms which contemplate the persecution of drug users. This situation is resolved by norm *disappropriation*, a variation of Acharya's description of norm displacement. In the case of Ukraine, this *disappropriation* manifests itself not by the failure of an international norm to overturn an existing local norm, as in displacement (Acharya, 2004), but by an international norm overturning another international norm at the stage of norm implementation, when international norms should integrate national practice. Although this pathway might have the same effect as the contestation of an international norm in that it does not get implemented, this is neither congruent nor explicitly expressed by the state authorities, although it makes it clear that drug policy norms have more domestic salience than harm reduction norms (Cortell and Davis, 2000) and therefore are higher up in the hierarchy of international norms in Ukraine.

The international drug policy system

According to Stoeva, international norms are divided into two main categories: non-security norms, where HIV/AIDS governance and human rights systems are located, and security norms involving issues affecting national security, such as the illegal drugs' trade (Stoeva, 2010). Modern international drug policy has two main objectives: first, the suppression of the production, distribution and use of all drugs (except those for medical and scientific purposes); and second, to ensure that controlled drugs are made available for medical purposes. This means that international human rights principles and norms are not contemplated or are at best secondary to security and crime control considerations in the international drug policy system (ICDP, 2011).

Drug trafficking today is a lucrative market worth hundreds of billions of dollars worldwide. Drug traffickers often form transnational networks that produce traffic and sell illegal drugs through several continents. Most countries are either on the supply or the demand side, or both. Illegal drugs are often associated with organised crime and seen as a threat to achieve “peace, security, and development” (UNODC, 2011: 8). In this context, there is no surprise that the international response to illicit drugs is high up in the IR agenda. Such a response aimed at controlling drug supply and drug demand is often referred to with the term ‘drug policy’. International drug policy is regulated by its own norm diffusion system (Krook and True, 2010) with a particular set of norms and standard (defined in a series of international treaties on narcotic drugs), and with its own international governance structures and actors, including, for example, the Commission on Narcotic Drugs (CND), the International Narcotics Control Board (INCB) and the UN Office on Drugs and Crime (UNODC).

The current international drug policy system has been largely shaped by the 1988 Convention against the Illicit Traffic in Narcotic Drugs and Psychotropic Substances. The 1988 Convention is often associated with the vague term ‘War on Drugs’, first introduced by US President Nixon in the 1970s and still being used in drug policy to this day as a way of describing a harder line against drug trafficking in drug control (ICDP, 2011). Authors are divided as to whether the 1988 Convention obliges signatories to criminalise drug possession as sustained by Room and Reuter (Room and Reuter, 2012). For Elliot et al., it expressly requires states to criminalise possession, but only if criminalisation is compatible with internal legislation (Elliot et al., 2005).

Drug policy and HIV among drug users and the hierarchy of international norms

The competition between international drug policy norms and international harm reduction norms (human rights-based HIV norms for drug users) to rule over the issue of illegal drug does not only take place in Ukraine, it illustrates an underlying tension in IR affecting all states in the use of illegal drugs. On the one hand there is the international socialisation of norms, understood as the process of interaction and negotiation among states leading to the reconciliation of states’ individual aspirations and widely accepted standards by other states (Schweller, 1996; Risse and Sikkink, 1999; Kravtsov, 2009). On the other, there is the state’s domestic political context (Cortell and Davis, 2000; Acharya, 2004; Brown, 2014). For governments charged with the responsibilities of addressing both drug use and HIV, the politics of dealing with both can be difficult.

The response to HIV among injecting drug users is at a crossroads in countries like Ukraine torn between harm reduction and drug policy principles. International and national drug policy, which is largely associated with state security and the fight against organised crime, often favours criminalisation of drug use and forced rehabilitation. In norm diffusion terms, this orientation is heavily biased towards norms that respond to appropriateness (responding to social rules condemning drug use) rather than to effectiveness (responding to medical evidence) (Farrell, 2001). A given country like Ukraine can be considered as appropriating two opposing international norms, while in fact, the actual implementation (compliance with and enforcement) of one over the other marks the hierarchy of norms, where norms form the international drug policy governance prevail, as well as the state priorities in terms of conciliation of international and national political pressures.

Drug policy norms often contradict human rights-based approaches to global health. Firstly, as explained at the beginning of this chapter, global health norms increasingly advocate for de-criminalisation of drug use and SMT, rather than rehabilitation. For Room and Reuter, the drug policy system's emphasis on criminalisation of drug use has "contributed to the spread of HIV, increased imprisonment for minor offences, encouraged nation states to adopt punitive policies (including executions, extra-judicial killings, imprisonment as a form of treatment)...and impaired the collection of data on the extent of use and harm of illicit drugs, all of which have caused harm to drug users and their families" (Room and Reuter, 2012:84). From a point of view of norm diffusion, these arguments are advanced by epistemological communities, as they are deeply rooted in scientific considerations (Stoeva, 2010).

Authors argue that criminalisation of drug use and denial of harm reduction programmes, including SMT, effectively deny individuals their fundamental right to the highest attainable level of health (Elliot, et al., 2005). This right is enshrined in both the Universal Declaration of Human Rights and the ICESCR, both key human rights norms, widely appropriated by states such as the Ukraine. There seems to be a wider agreement among authors as to tight drug control regimes contributing to create a 'moral environment' that legitimises human rights violations rather than constituting human right violations in themselves (Elliot, 2005; Costa, 2008).

Most governments feel the tension between on the one hand committing to adopting global health norms based on human rights to respond to HIV, and on the other dealing with a public security problem that requires reducing the supply and use of illicit drugs. There is in

fact a strong security approach often considered in HIV/AIDS governance, especially since the historic 2002 resolution by the UN Security Council making AIDS the first global health issue to be considered by the Security Council as an international security threat when it debated AIDS in Africa in 2002.⁷⁵ According to Elbe the international discourse of HIV and AIDS within the realm of security for which the Security Council is mandated, has not necessarily led to a mobilization of sovereign power in order to protect state's security to restrict essential freedoms of affected populations (Elbe, 2009).

In some countries like Ukraine, it is drug policies aimed to control illicit drugs which have in effect restricted essential freedoms of drug users at higher risk of HIV rather than HIV policies themselves. These countries, including China, the US and the Russian Federation, treat illicit drugs mainly as a public security issue that needs to be dealt with primarily by law enforcement structures which these states associate directly with high levels of violence (Room and Reuter, 2012). However, many Western countries, such as the UK, the Netherlands or Portugal as well as some developing or middle-income countries, such as Iran, favour harm reduction programmes, including SMT for drug users. In a world of limited resources, placing public security at the centre of drugs control automatically detracts resources from the provision of health in benefit of more support for law enforcement (Costa, 2008).

Tensions between tight drug control and human rights principles are ever so evident in IR. The US strongly opposes harm reduction approaches to reduce the adverse health and social consequences of drug use as central to preventing HIV transmission among people who inject drugs. Although for a few months in 2011 the US lifted its ban on syringe exchange-based HIV prevention programmes, the ban was reintroduced in 2012. The Russian Federation, with one of the fastest growing HIV epidemics among people who inject drugs, is also firmly opposed to harm reduction programmes. These tensions are also evident in the positions countries take when the international HIV response is formulated. For instance, although for a decade UN General Assembly declarations had been shaping the international response to HIV, injecting drug users were first named as a key population only in the 2011 UN General Assembly Political Declaration on HIV and AIDS (UNGA, 2011).

The 2011 Political Declaration reflects this tension by providing language in favour of both a drug policy articulation of the HIV response among drug users and harm reduction programmes and human rights-based approaches to the HIV response. Paragraph 26 of the Decla-

⁷⁵ United Nations Security Council Resolution 1308, 17 July 2000.

ration contains very clear drug control language. It notes “...with alarm the rise in the incidence of HIV among people who inject drugs and that despite continuing increased efforts by all relevant stakeholders, the drug problem continues to constitute a serious threat to, among others, public health and safety and the well-being of humanity, in particular children and young people and their families; and recognizes that much more needs to be done to effectively combat the world drug problem”. Support to harm reduction programmes is more mitigated. Signatories commit to “give consideration, as appropriate, to implementing and expanding risk and harm reduction programmes, taking into account the “WHO/UNODC/UNAIDS Technical Guide for Countries to set targets for universal access to HIV prevention, treatment, care for injecting drug users” in accordance with national legislation” (para.59.h).

In fact, the words harm reduction are not mentioned at all in the text (UNGA, 2011). The technical guide endorsed politically by this Declaration also falls short of endorsing the harm reduction architecture. The guide includes a core set of interventions considered as harm reduction, yet does not mention the term at all. Nor does the guide make any reference to human rights in the context of the HIV response among drug users and it even endorses compulsory treatment and rehabilitation centres in prisons and other closed settings, two interventions that are heavily criticised by authors and human rights organisation as breaching the human rights of drug users (see below) (WHO, UNODC, and UNAIDS, 2007: 8).

*On 20 May 2014, we were notified by the Russian authorities occupying Crimea that all substitution therapy programmes should stop. Overnight, more than 800 patients were left with nothing. We have opened a humanitarian corridor to continue providing therapy to displaced drug users, but we are just covering around 85, the rest must already be on the streets looking for heroin.*⁷⁶

The effect of the political charge of the international debate about drug policy norms and human rights norms is arguably felt in Ukraine more than in any other country. Excluding the US's stringent positions on drug policy explained above, the debate about drug policy illustrates the divide between the West, represented by the EU, to which some of the most active champions of harm reduction programmes belong, and the Russian Federation, a firm proponent of criminalisation of drug use determined to eradicate any harm reduction programme. The contradictions in public health and human rights policies as regards to drug users described throughout the case study are largely explained by the delicate political landscape in Ukraine, with a large

⁷⁶ Interview with an IHAA in Ukraine representative, phone conversation 23 June 2014.

portion of the population and political representatives divided between those who want closer ties with the EU and those who want to become closer to the Russian Federation (Samokhvalov, 2007). The invasion of the autonomous region of Crimea by Russian troops and its subsequent annexation by the Russian Federation exacerbated this divide and brought about a conflict between pro-West and pro-Russian actors which extended to other parts of Eastern Ukraine. The speed with which harm reduction programmes were closed in Crimea after the annexation by the Russian Federation in March 2014 speaks volumes about the political weight of the Russian Federation's drug policy positions and, in norm hierarchy language, the salience of drug policy over human rights and HIV norms.

Thus, the dynamics of coexistence of opposing international drug policy norms and human rights-based HIV norms to which the state has committed (through the Ministry of Interior for the former, and the Ministry of Health for the latter) provides an alternative to the theory in norm diffusion that norms which are not adopted outright by a state, are contested (Nadelmann, 1990; Kravtsov, 2009) or modified by the state following a congruence building model of modification whereby "states build congruence between transnational norm ...and local beliefs and practices... In this process, foreign norms, which may not initially cohere with the latter, are incorporated into local norms" (Acharya, 2004:241). In the case of harm reduction norms in Ukraine no such processes are necessarily taking place. The interference with drug policies mean that in reality the state as a whole is not compliant with the harm reduction norms state health representatives have committed to adopting and therefore international drug norms are indeed implemented by the state whereas the harm reduction norms are not. This situation is a direct consequence of the state being in fact represented by diverse and often competing internal structures committing to opposing state policies and therefore exposing inconsistent positions of the same state in various international norm diffusion processes.

Conclusion

As in the previous case of transgender organisations in Honduras, members of the CBOs of people who use drugs in Ukraine studied in this chapter own international human right norms as a way of countering social rejection and resisting state persecution, contributing to both boosting self-esteem and organising to claim rights denied by wider society and the state itself. However, the concentration of an ever-growing HIV epidemic among people who inject drugs in Ukraine has fostered the provision of HIV services by the CBOs representing this population

analysed in this chapter, generating local practice through the implementation of harm reduction programmes among drug users, which are constructed from human rights-based HIV norms. This has also contributed to the considerable influence that these organisations have had in the diffusion of such international norms into the national response to HIV.

This influence in domestic practice responding to HIV contrasts with the inability by the CBOs of transgender women analysed in Honduras to play a prominent role in their national HIV response. Besides the marked structural differences between the two countries and the differences in organisational strength and agency between the two sets of organisations, an essential factor contributes to this difference: the way the diffusion of international HIV norms among people who use drugs is constructed in Ukraine. Peer-to-peer services provided by CBOs of people who use drugs are recognised across HIV/AIDS governance as one of the most effective set of norms to respond to HIV among people who use drugs. The fact that harm reduction programmes for people who use drugs are deeply rooted in human rights principles (Eliot and Csete, 2005; OSI et al., 2008) help the organisations of people who use drugs analysed to use their participation in these programmes to empower their members and reinforce their structures to claim their rights and resist human rights violations. These CBOs have been able to create a space for themselves among international donors and relevant external human rights champions and have been able to strengthen their capacity to implement human rights norms in the context of HIV.

However, the CBOs of drug users studied in Ukraine have not been able to influence government policies and practices by law enforcement structures such as the police which violate the human rights of people who use drugs. This inability underlines the main points about norm diffusion theory to which this case study contributes. First, states cannot be considered as a single norm taking structure despite a common assumption in norm diffusion literature (Nadelmann, 1990; Cortell and Davis, 2000; Stoeva, 2010). Various competing structures within the state have simultaneously appropriated opposing international norms for different international governance systems: norms from the drug policy governance criminalising drug users on one hand, and harm reduction norms based on the respect of human rights of drug users from global HIV/AIDS governance on the other. This fact reinforces the importance of the phase of implementation of international norms in the study of norm diffusion. When two opposing international norms coexist, it is not possible for both to enter national practice, therefore, one of them is not effectively implemented by the state. This generates a norm *disappropriation* understood as the overturning of an international norm by another international norm

with more domestic salience. This circumstance illustrates how hierarchies among state structures and the international and national political tensions define hierarchies in the implementation of opposing international norms that the state has committed to adopting (Meyer et al., 1997; Finnemore and Sikkink, 1998). In the case of Ukraine, state security structures clearly prevail over public health structures when it comes to implementation of international norms in Ukraine and as result, even when people who use drugs have some access to harm reduction programmes, they are highly persecuted by law enforcement and other state structures.

In conclusion, although the CBOs of people who use drugs analysed in this case study have managed to infuse human rights principles to the HIV response by having a prominent role in the implementation of harm reduction programmes in Ukraine, they have not been able to influence the diffusion of human right norms for the protection and promotion of the human rights of drug users, who remain highly vulnerable to human rights violations such as police harassment and arbitrary detention. The following chapters describe situations where the CBOs of populations affected by HIV studied have gained more influence in the diffusion of international human rights norms.

6. CONTESTING CONTESTATION: ORGANISATIONS OF MEN WHO HAVE SEX WITH MEN AND OTHER LGBTI PEOPLE IN UGANDA

Introduction

The CBOs of men who have sex with men (MSM) and other members of the lesbian, gay, bisexual, transgender and intersex (LGBTI) population in Uganda studied in this case study have influenced the diffusion of international human rights norms protecting people from discrimination based on sexual orientation and gender identity by influencing key actors, in particular the judiciary to, at least temporarily, halt the contestation of such norms by the key state structures, in particular, the Ugandan Parliament. This influence is, however, limited since the government is failing to implement these norms by respecting, protecting and promoting the rights of LGBTI people and as of July 2015 members of parliament were still attempting to introduce legislation extending the repression of homosexuality.

This case study describes strategies the LGBTI organisations studied have followed to influence norm diffusion mirroring some of the evidence outlined in the previous chapters on CBOs in Honduras and Ukraine particularly, the building up of representation and sustainability and embracing international norms as organisations and among their members. However, CBOs in Uganda can also leverage their position of influence among external actors in a particular international governance system (for example, among international NGOs in the international human rights system) to influence other external actors in that and related governance systems (such as other states which are both key external actors in the international human rights system and donors in global HIV/AIDS governance).

The assimilation of international norms by the CBOs studied, either from global HIV/AIDS governance or from the international human rights system, is an important element in the strategies of influence of these organisations. This case study describes an evolution in this ownership which has proven highly adaptable over time to changes in both the internal socio-political context and in international HIV and the human rights governance systems. These adaptation strategies highlight the dynamism of CBOs as they navigate between translating international norms to conform to local customs in order to gain resonance among local actors on one hand (Acharya, 2004; Levitt and Merry, 2009; Stevenson, 2013), and owning them directly to try to influence external actors championing such norms (like international human rights NGOs) on the other. This balancing act partly questions the advocacy dilemma in

vernacularisation theory which claims that norms which do not challenge overtly a given local status quo have more chance of ending up integrated into national practice (Levitt and Merry, 2009).

The case study illustrates how various theories of norm diffusion work. For example, Uganda's rejection of LGBTI rights reflects the phase when international norms are resisted by state actors, prior to either being reinforced through international pressure and finally appropriated (Risse and Sikkink, 1998), or displaced by an existing local norm or custom that the new norm fails to overturn (Acharya, 2004). It also describes a boomerang effect whereby even when relevant Ugandan state actors choose to contest a norm, other national actors (the LGBTI organisations studied in this chapter) connect with international donors and NGOs to exert their influence on these state actors (Keck and Sikkink, 1998; Hertel, 2006).

In addition, the case study makes a relevant contribution of its own to norm diffusion theory regarding the behaviour of external actors (outsider proponents). Similarly to the incoherence that state structures often show in their behaviour on related norm diffusion processes described in the previous case of Ukraine, international actors, mainly donors and other states, show contradictions in their positions regarding the diffusion of opposing norms in a particular country. The US or the EU on one hand put pressure on Uganda to reverse its rejection of human rights norms protecting LGBTI, but they also contribute significantly to a national HIV response which ignores key international human rights-based HIV norms aimed at upholding the rights of this population. As in the case of states, external actors, including donors, too are represented by different structures in different norm diffusion process often exposing internal competition in their behaviour the diffusion of international norms.

Context: HIV and AIDS and men who have sex with men in Uganda

In the 1990s, Uganda was one of the countries most affected by the HIV and AIDS epidemic. The Government's initial response was courageous with a state-led campaign to raise awareness and counter discrimination. HIV prevalence levels among adults were reduced from 18% in 1992 to 6.4% in 2007. Uganda gained international recognition as a success story in the fight against HIV/AIDS. However, Uganda is still severely affected; over 1.5 million Ugandans are estimated to be living with HIV (UNAIDS, 2012a). In mid-2000s, the Uganda AIDS Commission and the Government of Uganda acknowledged that HIV rates of infection had begun to rise again (Uganda AIDS Commission, 2006). In 2011, the percentage of adults aged between 15

and 49 living with HIV had risen to 7.3% (Ministry of Health of Uganda, 2011), posing questions to Ugandans and international donors, which finance over 50% of the national HIV response, as to the effectiveness of the Ugandan HIV policies (Agaba, 2009).

Although the HIV epidemic has become generalised in Uganda, some people are at relatively higher risk of HIV infection compared to the general population. They include the partners and families of people living with HIV/AIDS, sex workers, MSM, members of fishing communities, adolescents living in extreme poverty such as street children, and internally displaced people and refugees. Up to 42% of new cases of HIV infection are amongst married couples, 22% from mother-to-child transmission, 21% among sex workers and 14% from casual sex (Uganda AIDS Commission, 2006). Sex workers, their clients and clients' partners contribute 10% of new infections, while MSM and people who inject drugs contribute less than 1% (Wabire et al., 2008). The Ugandan authorities do not report on the percentage of MSM or transgender people among people living with HIV (SGJN and Men Engage, 2013) and there is no official data on any aspect of the impact of HIV on MSM or transgender people, despite the fact that around the world these two populations are invariably at higher risk of HIV than any other subgroup within the LGBTI population and compared to any other population (UNAIDS, 2010).

Increasing internal opposition to the protection of LGBTI rights

Uganda is fertile ground for a myriad of internal and external actors who reject LGBTI people and who try to influence the state to either contest norms or policies aimed at protecting LGBTI people or to introduce more persecutory norms and policies against this population. Around 96% of Ugandans consider homosexuality morally unacceptable (The Pew Forum, 2010). Kaoma points out that social and political sentiment against homosexuality has been mounting over the past few years as a direct result of the influence of external actors with a religious agenda, namely US Christian conservative activists including Scot Lively; Pastor Rick Warren (Minister of the Saddleback Church in California); Lou Engle (Head of the Revivalist group, The Call and a leader in the right-wing New Apostolic Reformation movement); Don Schmierer (Exodus International) and Caleb Lee Brundidge (Extreme Prophetic Ministries).

These groups can all be assimilated with the notion of TANs as key external actors opposing norms protecting the rights of LGBTI people (Hertel, 2006). Ugandan religious leaders such as Julius Oyet or Joseph Mulinde, who spoke alongside these anti-gay activists from early 2009 in favour of a new bill against homosexuality, are also strong internal opponents to norms

protecting LGBTI rights. These conservative religious leaders denounce homosexuality as an imposed Western value alien to African culture. They present homophobia as an expression of resistance against post-colonial impositions about human sexuality and an attempt to preserve family values (Kaoma, 2009).⁷⁷ Although Kaoma gives greatest emphasis to the influence of American Evangelists on Ugandan society in the rise of anti-homosexuality in Uganda, consensus is in fact wide among religious leaders from all main affiliations in Uganda against homosexuality.⁷⁸

Heavy legal penalties for homosexuality-related manifestations have existed in Uganda for decades. Under current legislation, “carnal knowledge of any person against the order of nature” is classified among “unnatural offences” and is punishable with life imprisonment while the offence of attempting to commit “unnatural offences” is liable to seven years’ imprisonment (Penal Code Act, 1950). Although the Penal Code does not explicitly mention the term homosexuality, it is widely understood by law enforcement officers and the general population that unnatural offences refer to sexual practices between people of the same sex (Tamale, 2007). This repressive legal system both reflects the agency of internal opponents to LGBTI rights and incites rejection by wider society against this population widespread portrayed in the media.⁷⁹ Like in the case of Honduras, Uganda has ratified all relevant international standards protecting individuals against discrimination, including the ICCPR (accessed in 1995), and the ICESCR (accessed in 1987) (see Appendix 3).⁸⁰ However, the repressive legal and socio political context against LGBTI people in Uganda makes it clear that the state does not interpret the international human rights standards upholding the right to non-discrimination it has ratified to extend to discrimination based on sexual orientation or gender identity.⁸¹

Norm appropriation by LGBTI organisations and their members

This case study focuses mostly on the members and work of Sexual Minorities Uganda (SMUG), an umbrella organisation founded in 2004, representing 18 LGBTI organisations, the majority of LGBTI organisations in Uganda. SMUG defines itself as a coalition of human rights organisations, with a strong advocacy and campaigning profile. Most of the people interviewed

⁷⁸ Interview with Enid Wamami, Director of Partnerships, Uganda AIDS Commission, Kampala, 19 April 2013.

⁷⁹ Interview with Bishop Senyojo’s chapel attendant, Kampala, 21 April 2013.

⁸⁰ United Nations Treaty Collection, <https://treaties.un.org/>. Accessed on 11 June 2015.

⁸¹ Interview with Patricia Nduru, Uganda Human Rights Commission, 23 April 2013.

for this case study were members of SMUG, although members of Ice Breakers, which provides HIV/AIDS and other health related services for MSM and transgender people, Freedom and Roam Uganda (FARUG), a lesbian rights organisations, and Frank and Candy and Spectrum, both predominantly MSM organisations were also interviewed. None of these organisations is legally registered although they all have boards and other governance structures. Unlike in the case of Ukraine and Honduras, all of these organisations have a fairly diversified source of income from various international donors and human rights NGOs, and from 2012, also from HIV donors. SMUG is the strongest financially and structurally, with around four full-time personnel. Security is an issue for all of them as they are often raided by the police and their members outed in the media. Landlords often make them vacate their offices when they discover the scope of the organisation's work.⁸²

Much as in the cases of CBOs in Honduras and Ukraine, owning international human rights norms and to a lesser extent HIV norms, is essential in the identification of members with the CBOs which represent them studied in Uganda, and in the strategies and development of these organisations in a context of social rejection, discrimination and in this case, criminalisation. However, like in the case of transgender organisations in Honduras, this embracing means accepting identity constructs engrained in language and formulations used in the international human right system as well as in global HIV/AIDS governance, such as the notion of belonging to a large LGBTI community, being MSM or being gay. Such constructs do not necessarily correspond with the cultural, societal or religious profiles of CBO members, and on occasions lead to a paradoxical internal rejection of human rights norms and principles within the LGBTI population itself, consistent with the need for CBOs to become vernacularisers who adapt or translate such constructs to be understood by the populations they represent (Merry, 2009; Levitt and Merry, 2009; Orr, 2012).

*I am LGBT. I don't know, I've learned to define myself like that. I'm not sure what it means, by we all use it among us. Some of us don't like it, but they use it anyway. For me it's the same, gay, MSM, LGBTI, we know it's about us being brothers and sisters here.*⁸³

The acceptance of these constructs is to a large degree tactical as it serves the CBOs studied to reach out to international NGOs, international donors and other external actors both from the human rights system and the HIV/AIDS governance. These CBOs tread carefully between the translation of international norms and constructs to break the vernacularisation dilemma

⁸² Interviews with the directors of SMUG, Frank and Candy and Ice Breakers Uganda, Kampala, April 2013.

⁸³ Interview with a member of Frank and Candy, Kampala, 21 April 2013.

whereby these notions would need localisation to resonate among the LGBTI population on the one hand, and the direct appropriation of such notions to appeal to key external allies in trying to influence the state on the other. This choice contradicts in part the advocacy dilemma presented by Levitt and Merry suggesting that in order to be effective, CBO strategies should conform to readily accepted strategies among local actors without an upfront challenge of status quo (Levitt and Merry, 2009) since the appropriation of global constructs around sexual orientation and gender identity represent a significant challenge to the internal status quo. The appropriation of international HIV norms by the LGBTI organisations studied has also been tactical and has evolved to react to changes in policies by internal and external actors of the HIV response in Uganda. However, there is wide consensus among the LGBTI people interviewed that HIV and AIDS matter considerably to them considering how hard the epidemic has hit this population over the past decades.

Appropriation of human rights norms on sexual orientation and gender identity

LGBTI organisations overtly place the promotion of international human rights norms at the centre of their work, with a strong focus on the notion of non-discrimination as the guiding principle; although these norms do not refer explicitly to LGBTI people, they extend their protection against discrimination based on sexual orientation and gender identity under the category “other status”.⁸⁴

*It's all about fighting discrimination. If we were not discriminated against because of our sexual orientation, how we look, because we might look effeminate and so on, all our rights would be respected, from finding a job to not being arrested by the police...We are not claiming rights for ourselves, we just want to have the same rights as everybody else in Uganda, which is what human rights say, and the constitution say, we are citizens like everybody else. That is the main goal of our organisations.*⁸⁵

The CBOs studied also embrace principles related to LGBTI rights as a public expression of a sexual orientation or gender identity in their own discourses to define their constituency and claim the rights of the population they represent as a core objective of their action. MSM in Uganda are mostly integrated in larger LGBTI organisations as a reflection of the categorisation

⁸⁴ The ICESCR, for example states: “The States Parties to the present Covenant undertake to guarantee that the rights enunciated in the present Covenant will be exercised without discrimination of any kind as to race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status”. Part II. Article II.

⁸⁵ Interview with Jeff Owaro, Director Civil Society Coalition on Human Rights and Constitutional Law, Kampala, 22 April 2013.

of this population given under the international human rights system. According to an LGBTI leader, “This is needed to get international recognition and access funding”.⁸⁶

*When I first came in [CBO of LGBTI people] I just couldn't believe there were human rights called LGBTI rights. All my life I've have been called gay, or homosexual, as if it meant I had no rights....It was like being born again to learn that I was still worth it.*⁸⁷

A growing number of members of LGBTI populations came out expressing their sexuality publically, often to rebel against repressive or traditional social structures.⁸⁸

*Talking about human rights is not so effective. When I talk to elders, religious leaders, even my family, they don't understand these concepts, because they are not part of the traditions.*⁸⁹

*Human rights widen the understanding in people, but the concept itself is problematic here. Those who understand it are already converted. Those who don't will never click. They say: 'You are asking for the right to have same sex'.*⁹⁰

Many of the CBO members interviewed joined LGBTI organisations not just for the support they may receive, but to be actively involved as activists. It is a way of revealing their sexual orientation or gender identity before their own families and friends.

*When you heard you are LGBTI it was confusing, at first I didn't even know what that meant, and I had never seen a transsexual in my life. But when I realised what others within the LGBTI community were going through, I thought, hey, they are not different from me. It sort of makes sense we are together fighting for our rights. It feels better to see that I am not alone.*⁹¹

For Amory, the growing recognition of terms such as LGBTI by sexual minorities across the world draws on the development of a human rights discourse that identifies lesbian and gay rights as human rights (Amory, 1997). This is a clear sign of the ownership of human rights principles which tend to describe all various populations representing sexual diversity as a unified LGBTI community of right holders (OHCHR, 2012).

⁸⁶ Interview with Frank Mugisha, Executive Director of SMUG, Kampala, 22 April 2013.

⁸⁷ Interview with a member of Frank and Candy, Kampala, 21 April 2013.

⁸⁸ Interview with a representative from Sexual Minorities Uganda, Kampala, 19 April 2013.

⁸⁹ Interview with a representative from SMUG, Kampala, 19 April 2013.

⁹⁰ Interview with Jeff Owaro, Director Civil Society Coalition on Human Rights and Constitutional Law, Kampala, 22 April 2013.

⁹¹ Interview with a member of Ice Breakers Uganda, Kampala, 20 April 2013.

When I entered [Ice Breakers], it was like coming out. I knew it was going to be like that. I was exposed in the media. My brother found out and was angry with me because I hadn't told him. I could tell him about my work and my rights. He is ok with me now, but I haven't told my family yet.⁹²

However, there is considerable debate about members as to whether these terms indeed reflect their reality or are just tactically adopted. This suggests that such assimilation is not straight-forward and that CBOs need to translate international norms to relate to the local context in order for these norms to resonate among their members (Levitt and Merry, 2009; Orr, 2012). Gay men and other sexual minorities are often divided as to whether terms like LGBTI reflect their reality accurately, and whether the LGBTI population actually constitutes a distinct community of people with common characteristics.⁹³ For the lesbian women interviewed, for example, being included in an LGBTI community has given them a wider platform to voice their messages.

I don't belong to the LGBTI community. I belong to the women community, I identify with those who have my same issues as a woman, including transgender men, because physiologically, they have similar issues to mine. But also socially, as they might feel harassed by men, the same way I am.⁹⁴

Much as in the case of CBOs of transgender women in Honduras, the links among the various parts of the LGBTI population often reflect more a common experience of suffering the same kind of social rejection and discrimination and persecution by law and in practice than a shared identity or a sense of belonging.⁹⁵ Whereas Honduran transgender women feel closer to other women in the LGBTI movement in terms of the gender they identify with, the lesbian women interviewed in Uganda identify more with transgender men. In both cases however, CBOs representing transgender people or lesbians claim to be part of the LGBTI community.

⁹² Interview with an administrator at Ice Breakers, Kampala, 20 April 2013.

⁹³ Interviews with a representative from SMUG, Kampala, 19 April 2013, and Bob Bwana, Administrator, Ice Breakers, Kampala, 20 April 2013.

⁹⁴ Interview with a Lesbian activist, FARUG, Kampala, 23 April 2013.

⁹⁵ Interview with a LGBTI activist of Civil Society Coalition of Human Rights and Constitutional Law, Kampala, 19 April 2013.

Appropriation of international HIV norms by LGBTI organisations

The origin of the organisation of LGBTI people in Uganda as a movement with defined political strategies can be traced back to the late 1990s.⁹⁶ Early gains on the access of this population to the HIV response were significant. UNAIDS opened a dialogue with national institutions on it when LGBTI issues around HIV were still barely being debated across the world. In 2002, the Uganda AIDS Commission, as a representative of the state in the HIV sector included MSM as a key target group in the National Strategic Plan to fight AIDS, stating the state-led national practice against the epidemic. This attention was however short-lived and no HIV programmes for MSM were implemented under subsequent strategic plans.⁹⁷ In parallel, homophobia mounted among society and as a consequence, the integration of MSM in the HIV response came off the agenda.⁹⁸ By the mid-2000s, it became clear among LGBTI activists that the HIV advocacy route was not going to be a good avenue to advance LGBTI rights. The Ugandan HIV movement also reflected widespread social homophobia.⁹⁹ However, given the high HIV incidence rate among MSM and transgender people, the Ugandan LGBTI population's relation with HIV has always been close.

I first became an HIV activist because of family members dying of AIDS. I volunteered for TASO [The AIDS Support Organisation] on HIV prevention while studying at university. I was in the closet and did not realise at the time that the response wasn't getting to us [MSM]. I remember now that all materials were for heterosexual people. Nothing was directed to men who have sex with men.¹⁰⁰

Although for much of the 2000s LGBTI organisations moved away from trying to influence the diffusion of HIV norms in Uganda, organisations such as Ice Breakers, Spectrum, Youth on the Rocks Foundation and other LGBTI organisations continued to provide basic HIV prevention services for the LGBTI population. This limited local practice bypassed national policies on HIV and helped strengthen the role and legitimacy of some CBOs among LGBTI people.

I might be more exposed as a gay man coming here [to Ice Breakers], from that point of view I'm less safe. But belonging [to this organisation] I feel safer being who I want to

⁹⁶ Interview with Frank Mugisha, Executive Director of SMUG, Kampala, 22 April 2013.

⁹⁷ Interview with Denis Ojok, Zonal Coordinator, Uganda AIDS Commission, Kampala, 19 April 2013.

⁹⁸ Interview with Enid Wamami, Director of Partnerships, Uganda AIDS Commission, Kampala, 19 April 2013.

⁹⁹ Interview with an LGBTI activist from the Civil Society Coalition of Human Rights and Constitutional Law, Kampala, 19 April 2013.

¹⁰⁰ Interview with a representative from SMUG, Kampala, 19 April 2013.

*be and not being in the closet. Here, we know about HIV, we stay healthy and we support each other morally...We also protect each other, because together we know the risks around us and can act together.*¹⁰¹

As in the case study of people who use drugs in Ukraine and transgender sex workers in Honduras, many activists first got to know about the organisations when approaching them for HIV services. For many, the first approach to these organisations was around shelter, health and psychosocial support, sometimes physical protection from social intimidation.

CBOs' strategies and the behaviour of internal actors in norm diffusion

Although they managed to attract key external allies, the LGBTI organisations studied needed to adapt their strategies to react to the internal social and political landscape that has surrounded the debate about homosexuality in Uganda over the past 15 years. Much of this debate has actively been stirred by the positioning of the national leadership about human rights and HIV norms regarding sexual minorities.¹⁰² Unlike in the case of strategies towards external actors, with a few exceptions among health and judicial authorities, Ugandan LGBTI organisations have been unable to influence directly the state and other key internal actors, including the media, and religious and community leaders, although the fact that the proposed anti-homosexuality legislation was only in force for a few months in 2014 demonstrates the validity of the strategies of these organisations in leveraging the influence they do have with external actors (explored further in this chapter).

The government's declared contestation of LGBTI rights reflects the phase in norm diffusion theory where international norms are resisted by states, prior to either being reinforced through international pressure and finally appropriated (Risse and Sikkink, 1998) or displaced by an existing local norm or custom it fails to overturn (Acharya, 2004). However, as in the previous case study of Ukraine, various state structures show contradictory behaviour in relation to the diffusion of international norms affecting the LGBTI population. These contradictions underpin the essential role of national leadership in the rejection or adaptation to the local context (*glocalisation* in Brown's terminology) of international norms (Brown, 2014). However, whereas Brown focuses mostly on the role of health leaders within the diffusion of global health norms, this case study shows that other national leaders can also play

¹⁰¹ Interview with an administrator from Ice Breakers, Kampala, 20 April 2013.

¹⁰² Interview with a representative from Community Health Alliance Uganda, Kampala, 22 April 2013.

a significant role and expose contradictions across state structures. Increasingly health authorities appropriate international human rights-based HIV norms aimed at protecting sexual minorities, whilst significant parts of the state, including the President, the Minister of Internal Affairs and others, overtly contest international human rights norms upholding LGBTI rights.

Contesting Uganda's contestation of international norms protecting LGBTI people

Throughout the 2000s, the LGBTI movement grew and strengthened. It is from that stage that the first attempts to influence the diffusion of human rights norms by CBOs of LGBTI people can be dated. The creation of SMUG in 2004 responded to the need to step up advocacy and campaigning to help visualise the LGBTI population.¹⁰³ The prevailing sentiment for many of these activists was the need to counter the widespread view that there were no gay people in Uganda in order to participate in decision-making processes that affected them, in other words, to influence the diffusion of norms affecting their lives.

*At the time [early 2000s], we realised that we had to organise and become visible as a group, because we were told we didn't exist by everybody: the government, the pastors, the media...There wasn't any choice for us but to become visible if we wanted to survive.*¹⁰⁴

With exposure and public demand of rights came homophobic reactions from key internal actors, in particular the media and social and religious leaders. Between 1999 and 2009, the debate about homosexuality was very present and open in Ugandan society. It was also polarised, with most people aligning to either extreme end of arguments, which the national media served to voice out.¹⁰⁵

Many gay men and women feel they could come out as they saw they weren't alone. MSM could come to us [LGBTI organisations] for support. This period [2004-2009] brought the best of us and a sense of solidarity and belonging for many. It isn't that we felt we were safer altogether, coming out is always exposing yourself more, but it felt

¹⁰³ Interview with Frank Mugisha, Executive Director of SMUG, Kampala, 22 April 2013.

¹⁰⁴ Interview with Jeff Owaro, Director Civil Society Coalition on Human Rights and Constitutional Law, Kampala, 22 April 2013.

¹⁰⁵ See for instance: The Monitor, 'Homosexuality is as African as the Baobab tree', 10 February 2003; Sunday Pepper, 'Homos and lesbos deserve no respect', 10 September, 2006; New Vision, 'Homos suffer because of stigma', 28 June 2006; Weekly Observer, 'Why is church obsessed with gays?', 13 June 2007; Daily Monitor, 'Homosexuality is a real vice', 20 September 2007; Monitor Thursday, 'Homosexuality is not genetic', 27 September 2007; Daily Monitor, 'Mufti Wants Gays Abandoned on Islands', 15 October 2007.

*that we could be ourselves and be relatively safe, that was better.*¹⁰⁶

The attention that religious and social leaders gave to homosexuality vastly contributed to politicians beginning to publicly express their concern as early as the late 1990s (Anderson, 2007). This change in the discourse of some key representatives of the state is consistent with Keohane and Koh in their description of the phases of internalisation of norms by state representatives, which often involve changes in political discourses. However, in this case such changes showed rejection of international human rights norms protecting people based on sexual orientation and gender identity (Keohane, 1989; Koh, 1997), embracing instead opposing norms based on heteronormativity and patriarchy and other religious and traditional principles condemning homosexuality. Between 1999 and 2008, a number of high-ranked politicians used the media to voice their opposition to homosexuality, some of whom, including the author of the Anti-homosexuality Bill, David Bahati, MP, were allegedly closely linked to American evangelist groups (Sharlet, 2009).

President Museveni reportedly said in 1999, “I’ve told the CID [Criminal Investigations Department] to look for homosexuals, lock them up and charge them”.¹⁰⁷ The same year, the Minister of Security, Muruli Mkasa reportedly referred to homosexuality as “a bad crime”.¹⁰⁸ In 2004 and 2005 the State Minister of Information, Nsaba Buturo, condemned the ‘promotion of homosexuality’ by the media.¹⁰⁹ By 2007, Mr Buturo, who had become Minister of Ethics and Integrity, was already calling for a ‘tough anti-gay law’,¹¹⁰ which was reportedly already being drafted by September 2007.¹¹¹ The Anti-homosexuality Bill tabled in Parliament in 2009 represents the main landmark in Uganda’s rejection human rights norms as regards to LGBTI people, tainted with allegations of widespread human rights violations such as arbitrary arrest and police harassment committed against this population at the time of its introduction in Parliament (Amnesty International, 2008a, 2008b; Tamale, 2009). The bill contained measures to criminalise the promotion of homosexuality and compel HIV testing in certain circumstances. It proposed life sentences for same-sex marriages and the death penalty for

¹⁰⁶ Interview with a programme director at Ice Breakers, Kampala, 22 April 2013.

¹⁰⁷ The New Vision, ‘Arrest Homos, Says Museveni’, 28 September 1999.

¹⁰⁸ The Monitor, ‘Homos in West are Beasts-Minister’, 12 November 1999.

¹⁰⁹ The New Vision, ‘Radio samba was publicly promoting homosexuality’, 12 October 2004; The New Vision, ‘Why does New Vision promote homosexuals?’, 24 February 2005.

¹¹⁰ Sunday Vision, ‘Tough Anti-gay Law Due’, 26 August, 2007.

¹¹¹ The New Vision, ‘Govt Drafts Homosexuality Bill’, 28 September 2007.

“aggravated homosexuality”.¹¹² The bill also created the offence of failing to report knowledge of any violations of the new provisions within 24 hours and widened the offence of homosexuality to include the intent to commit homosexuality (Anti-homosexuality Bill, 2009).

The text was contrary to a number of basic human rights norms previously appropriated by Uganda and incorporated in the Ugandan constitution (Amnesty International, 2014), including the right to freedom of expression, freedom of thought, conscience and religion, freedom of peaceful assembly, freedom of association, liberty and security of the person, privacy, the highest attainable standard of health, and life (OHCHR, 2014). The bill was provisionally withdrawn in 2010. It was re-introduced in October 2011 and then on several other occasions.¹¹³ It was finally passed by Parliament in December 2013 and signed into law by President Museveni in February 2014. It was declared unconstitutional by the Constitutional Court in July 2014 as the passing in Parliament did not obtain the necessary quorum, and therefore repealed.¹¹⁴

The introduction of the bill provoked another shift in the strategy of the LGBTI organisations studied. Two parallel strategies ensued: on the one hand, the CBOs deemed it necessary to raise awareness of the bill among external actors (international NGOs, progressive governments and other outsider proponents of human rights norms) so that pressure was mounted on key state representatives (President Museveni and his government, and National Assembly notably) to prevent the bill becoming law and protect the LGBTI population. The second strategy was to reach out to other human rights and larger civil society organisations outside the LGBTI movement, so that, internally, there was a common front among key internal actors, especially civil society representatives, against the bill. LGBTI activists created the Civil Society Coalition on Human Rights and Constitutional Law (Civil Society Coalition), which, despite its title, focused almost exclusively on opposing the bill in Court and promoting LGBTI rights through advocacy. This latter strategy had much less of an impact.¹¹⁵ The development of

¹¹² “Aggravated homosexuality” is defined by the bill as “(a) person against whom the offence is committed is below the age of 18 years; (b) offender is a person living with HIV; (c) offender is a parent or guardian of the person against whom the offence is committed; (d) offender is a person in authority over the person against whom the offence is committed; (e) victim of the offence is a person with disability; (f) offender is a serial offender, or (g) offender applies, administers or causes to be used by any man or woman any drug, matter or thing with intent to stupefy, overpower him or her so as to thereby enable any person to have unlawful carnal connection with any person of the same sex”.

¹¹³ Interview with Patricia Nduru, Uganda Human Rights Commission, 23 April 2013.

¹¹⁴ BBC, ‘Uganda court annuls anti-homosexuality law’, 1 August 2014.

¹¹⁵ Interview with Jeff Owaro, Director Civil Society Coalition on Human Rights and Constitutional Law, Kampala, 22 April 2013.

the Civil Society Coalition around the demand of human rights for all, helped attract Ugandan human rights organisations interested in joining forces to demand wider space for civil society and. The coalition petitioned successfully against the bill before the Constitutional Court. However, for a large number of internal actors including state representatives, the Coalition was perceived solely as a platform to promote LGBTI rights.¹¹⁶

*The [Anti-homosexuality] Bill has further divided Ugandans as regards to human rights and contributed to mix morality and religion with politics. The bill has made many question international law and how it is formulated and fear foreign imposition in other difficult issues, such as such abortion or polygamy.*¹¹⁷

The Anti-homosexuality Bill had wide support across other state structures, the legislative in particular, including the House Speaker, Rebecca Alitwala Kadaga, some particularly vocal government ministers, and the majority of MPs across all political parties.¹¹⁸ There were however also dissenting voices in the Ugandan Parliament itself. In November 2012, three MPs from opposition parties produced a minority report on the bill, claiming that “(w)hat two consenting adults do in the privacy of their bedroom should not be the business of this Parliament.”¹¹⁹

While the general political environment among internal actors is evidently overwhelmingly hostile to an international norm protecting the rights of the LGBTI population, some of the LGBTI organisations studied gained considerable influence on another key state structure, the judiciary, mostly through strategic litigation in courts.¹²⁰ In a landmark case brought in 2008 by LGBTI activists Yvonne Oyoo and Juliet Mukasa v. the Attorney General, the High Court ruled that the rights guaranteed by the Uganda’s Constitution apply to LGBTI people regardless of their sexual orientation or gender identity. The High Court also ordered damages to be paid to two other LGBTI activists after police unlawfully seized their documents and treated them in a cruel, inhuman and degrading manner (Kaoma, 2009). David Kato, from SMUG, and two other LGBTI activists successfully sued Rolling Stone, a Kampala weekly newspaper which had exposed their identities as homosexuals. On 3 January 2010, a High

¹¹⁶ Interview with Jeff Owaro, Director Civil Society Coalition on Human Rights and Constitutional Law, Kampala, 22 April 2013.

¹¹⁷ Interview with Priscilla Nyarugoye, Vulnerable Groups Officer, Uganda Human Rights Commission, 23 April 2013.

¹¹⁸ Interview with programme director at Ice Breakers, Kampala, 22 April 2013.

¹¹⁹ Office of the Clerk to Parliament of Uganda, *Minority Report by members of the Sectorial Committee on Legal and Parliamentary Affairs on the Anti-Homosexuality Bill*, 2009. November 2012.

¹²⁰ Interview with Jeff Owaro, Director Civil Society Coalition on Human Rights and Constitutional Law, Kampala, 22 April 2013.

Court judge ruled that the publication had violated their constitutional rights to privacy and ordered compensation (IHAA, 2011b). And, as mentioned above, in their most significant judiciary win, LGBTI CBOs under the banner of the Civil Society Coalition successfully challenged the Anti-homosexuality Act, which was declared null and void by the Constitutional Court in August 2014.¹²¹

The diffusion of international HIV norms into national HIV/AIDS governance

Uganda's opposition to non-discriminatory international norms as regards to sexual minorities has had a direct impact on national HIV/AIDS governance, which has largely disregarded human rights-based HIV norms among LGBTI people. The national HIV response has focused mostly on biomedical responses for the larger population in the context of a generalised HIV epidemic to the detriment of minority populations at higher risk of HIV.¹²² This policy, along with widespread social perception that HIV is transmitted by homosexuals contributed to seriously undermine the access of MSM to HIV prevention and treatment programmes (Long et al., 2003; Tamale (Ed), 2007). Many feel unable to seek medical help or advice fearing the consequences of revealing their sexuality:

*My sexual orientation and acts we involve in puts me very much at risk. You cannot go to the doctor and tell him that something happened to you. You have to give the wrong information so the doctor ends up treating you wrongly. Not because it is his mistake but because you gave the wrong information. If the doctor knew the truth, he would either turn aside or look at you thinking, who is this one now?*¹²³

The passing of the HIV/AIDS Prevention and Control Act by Parliament in August 2014, demonstrates that Uganda adopts international HIV norms from global HIV/AIDS governance which are not human rights-based. The act includes provisions for mandating compulsory HIV testing in certain circumstances in violation of the right to informed consent, and criminalising the intentional transmission of HIV to another person, likely to act as a deterrent to finding out one's HIV status. It may also discourage people from seeking voluntary counselling and testing (VCT) services, one of the most widely accepted international human rights-based HIV norms.¹²⁴ The Act also requires health personnel to disclose the HIV status of their HIV positive

¹²¹ BBC, 'Uganda court annuls anti-homosexuality law', 1 August 2014.

¹²² Interview with Enid Wamami, Director of Partnerships, Uganda AIDS Commission, Kampala, 19 April 2013.

¹²³ Interview with an activist from Spectrum, Kampala, 22 April 2013.

¹²⁴ Interview with an activist from Health Gap, Kampala, 21 April 2013.

patients in violation of patients' human rights to privacy and confidentiality (HRW, 2009).

I went to the clinic asking doctors to provide HIV counselling to my LGBTI colleagues. They were afraid they could go to prison for promoting homosexuality if they did so. I told them that there wasn't any law in force that would expose them. They thought the [Anti-homosexuality and HIV/AIDS Prevention and Control] bills were already in place and they would be seen as 'accomplices'.¹²⁵

However, it is significant that the representatives of the state within national HIV/AIDS governance, in particular, the Ministry of Health, behave very differently from other state representatives in the executive and the judiciary in relation to the LGBTI population. Despite the internal social and political hostility, the outreach work of CBOs affiliated to SMUG, Ice Breakers in particular, among international NGOs and other external actors attracted growing international donors' interest.¹²⁶ This clinic had been operating clandestinely, without permits and with limited funding throughout the 2000s.¹²⁷ From 2011 onwards the state health authorities showed signs of openness to the provision of HIV and other health services to LGBTI people through services such as the Most at Risk Populations Initiative (MARPI) programme, which complements the work of the Ministry of Health at Mulago, the largest public referrals hospital in Kampala. The MARPI clinic is now officially in partnership with the CBO-led Ice Breakers outreach clinic for MSM. The partnership includes the provision of doctors from the public health care service to the Ice Breakers clinic and joint outreach campaigns in provinces all around Uganda.¹²⁸

LGBTI people come to our outreach [Ice Breakers] clinic because they know the organisation hosting it is LGBTI. And from this clinic, they are accompanied to the MARPI Clinic in the [Mulago] government hospital. Very few people know it, but the government is helping MSM with HIV and other medical treatment...If it wasn't for the gay outreach clinic, not a single MSM would go to MARPI. But it is not easy, in 2012, the government wanted to close the referral clinic for promoting homosexuality and the Minister [of Health] had to intervene saying that the clinic collaborated with the

¹²⁵ Interview with Jeff Owaro, Director Civil Society Coalition on Human Rights and Constitutional Law, Kampala, 22 April 2013.

¹²⁶ Interview with a political secretary at the British High Commission, Kampala, 23 April 2013.

¹²⁷ Interview with a programme director at Ice Breakers, Kampala, 22 April 2013.

¹²⁸ Interview with Denis Ojok, Zonal Coordinator, Uganda AIDS Commission, Kampala, 19 April 2013.

*state health service and was doing a good job.*¹²⁹

According to Brown, “...although the influence of global policy can play an important guiding role, health norms are never transcribed straightforwardly into national systems and a central element of successful health governance remains vested in the nation and the leadership role it exerts” (Brown, 2014:878). The fact that HIV services for LGBTI people even with the participation of state health care facilities are under threat by some state representatives themselves underpins the importance of national leadership within and outside national health governance in the implementation of global health norms. As in the case of harm reduction programmes run by CBOs in Ukraine, in Uganda too, LGBTI organisations are contributing to the national response to HIV with the recognition of the Ministry of Health, while being persecuted by most other state structures, including the ministries of Ethics and Integrity, Security, Information and law enforcement institutions.

Strategies of LGBTI organisations to influence external actors

The influence of the Ugandan CBOs studied among external actors within the human rights norm system has been much more critical than their inroads among outsider proponents of the diffusion of international HIV norms. This is largely due to the fact that, unlike in the case of Ukraine, LGBTI organisations in Uganda have not been given a role in the implementation of the HIV response until very recently which they could leverage to influence the state to introduce human rights-based HIV responses among LGBTI people. However, these CBOs have managed to leverage their influence among external proponents of international human rights norms, such as human rights NGOs, other influential states (US, EU member states), and institutions of the international human rights system (UN High Commissioner for Human Rights) to eventually influence some structures of the state in charge of the HIV response.

From a norm diffusion theory point of view, the LGBTI CBOs in Uganda studied in this chapter have contributed to a boomerang effect whereby even when the Ugandan government chose to reject international norms protecting LGBTI people, these organisations connected with international donors, international NGOs and other TANs to exert their influence on the state (Keck and Sikkink, 1998; Hertel, 2006). These external actors have campaigned all around the world against the bill, obtaining widespread support from key actors mostly in Western countries, and a number of states have reacted strongly against state-sponsored

¹²⁹ Interview with a medical practitioner in both MARPI and Ice Breaker’s MSM clinic, Kampala, 20 April 2013.

homophobia in Uganda. As an example of such recognition among external actors, Frank Mugisha, executive director of SMUG, and other the members of the Civil Society Coalition received the US State Department's 2011 Human Rights Defenders Award from the then US Secretary of State, Hilary Clinton.¹³⁰

Ugandan LGBTI organisations have adopted constructs such as the existence of an LGBTI community as a deliberate strategy to attract the support of these international actors at the risk of generating further opposition from national actors and even their own populations.¹³¹ This confrontational strategy before the state contrasts with the consideration of local civil society organisations as adapters or translators of global norms to local realities as a way to circumvent an advocacy dilemma regarding international norms which pushes these organisations to align themselves with local strategies, they are “more readily accepted but represent less of a challenge of status quo” (Levitt and Merry, 2009: 458).

A key contribution to norm diffusion theory in this section is that international actors, mainly donors and other states, show contradictions in their positions regarding the diffusion of opposing norms by a particular state. The way in which the US or the EU put pressure on Uganda to reverse its contestation of human rights norms protecting LGBTI rights while simultaneously contributing to a national HIV response which ignores key international human rights-based HIV norms aimed at upholding the rights of this population illustrates such incongruence well. As in the case of states, external actors too are represented by different structures in different norm diffusion process often exposing their internal contradictions regarding the diffusion of international norms.

An unprecedented reaction by actors of the international human rights system

The unprecedented worldwide rejection of the bill put enormous pressure on key donors, other states, international NGOs and organs of the international human rights system to question President Museveni and his government. As a result, almost all Western countries rallied to condemn the bill, especially Canada, the Obama administration in the US, and UK Prime Minister David Cameron, who threatened to cut aid to countries such as Uganda where the rights of the LGBTI people were not respected.¹³² This pressure exacerbated by corruption

¹³⁰ The Washington Blade, 'Clinton honors Ugandan human rights advocates' <http://www.washingtonblade.com/2012/08/03/clinton-honors-ugandan-human-rights-advocates/#sthash.kUduzvM5.dpuf>, 3 August, 2012, accessed on 4 May 2014.

¹³¹ Interview with Frank Mugisha, Executive Director of SMUG, Kampala, 22 April 2013.

¹³² BBC, 'Cameron threat to dock some UK aid to anti-gay nations', 30 October 2011.

scandals which had an impact on donors' support to Uganda,¹³³ modified President Museveni and his government's standing in relation to the bill.¹³⁴

Homosexuals have existed in our part of Africa, they were never persecuted, they were never discriminated...they were also never promoted. So the problem is on the promotion of homosexuality...In our traditional society, the homosexuals would be known; it would not be approved but would be ignored. President Yoweri Museveni, 2012.¹³⁵

However, the bill also became a bargaining tool for President Museveni in his relations with key actors of a different international governance system: international security. Uganda is a geo-political and military powerhouse and the main ally of the West in a highly volatile region. From that point of view, the bill was unlikely to erode the relationship between Uganda and its allies. Furthermore, the discovery of new oil deposits in 2010 brought new economic and commercial avenues for collaboration between Uganda and the rest of the world, strengthening Uganda's capacity to resist international pressure.¹³⁶

As far as the impact of this contestation of human rights norms by the state on the development of the LGBTI organisations studied is concerned, the creation of organisations pursuing the rights of LGBTI people, or deemed to promote LGBTI rights, may in fact have unintentionally served the objectives of politicians and religious and social leaders opposed to human rights norms promoting LGBTI rights. These opponents see in the creation of such structures the confirmation of a gay agenda to promote alien LGBTI rights, and recruit and indoctrinate youth. For some LGBTI people in Uganda, it is indeed the official discourse by state representatives against homosexuality, which has contributed to the development of a wide and inclusive LGBTI movement.

*We were just a few scattered groups, but when Museveni came out to attack us and put us all in the same basket as evils, he made us join forces and become stronger.*¹³⁷

In turn, the fight against this perceived Western homosexual agenda served the authorities as

¹³³ In late 2012, Britain, Sweden, Ireland, Denmark, the European Union Commission and others suspended portions of their aid budgets over allegations that money intended for peace recovery programmes in the north of Uganda had ended up in the private bank accounts of officials in the prime minister's office (Devex, 'In Uganda, donors divided on response to aid embezzlement scandal', 10 December 2012).

¹³⁴ Interview with a political secretary at the British High Commission, Kampala, 23 April 2013.

¹³⁵ AFP, 'Ugandan gays are not persecuted: President', 22 February 2012.

¹³⁶ BBC, 'Uganda confirms new oil deposits', 18 September 2012.

¹³⁷ Interview with an administrator, Ice Breakers, Kampala, 20 April 2013.

an alibi to control and repress other civil society organisations, deemed dangerous to the government's own political agenda.¹³⁸ As mentioned earlier the space of civil society is being reduced. A number of organisations risk being de-registered for promoting homosexuality, including not only those providing HIV services for MSM, but also NGOs advocating non-discrimination or universal rights and international organisations from countries whose governments have been vocal against homophobia in Uganda.

*Cracking certain NGOs in the name of fighting homosexuality is a publicly accepted way of taking on organisations that are otherwise openly critical of the authorities.*¹³⁹

Large international LGBTI NGOs such as the International Lesbian and Gay Association (ILGA), 76 Crimes, All Out, or ARC International, and mainstream human rights campaigning organisations, including Amnesty International and Avaaz, increased their pressure on Uganda, contributing to the bill still not being passed for years. All these organisations explicitly supported SMUG and partner LGBTI organisations voicing out their demands prior to and during debates in Parliament around the bill.¹⁴⁰ This pressure is consistent with, and contributed to, increased attention to LGBTI rights by key actors in the international human rights system from 2010 onwards, illustrated by public pronouncements of UN Secretary General Ban Ki-Moon in support of LGBTI rights,¹⁴¹ and the first ever resolution on Sexual Orientation and Gender Identity at the UN Human Rights Council, which Uganda, a Council member at the time, voted against. The Council Resolution expressed “grave concern” at violence and discrimination against individuals based on their sexual orientation and gender identity (UN Human Rights Council, 2011).

An important consequence to the vast alignment of external actors with the cause of LGBTI organisations in Uganda is that, despite overwhelming opposition to human rights norms protecting LGBTI people by key norm takers in Uganda, the contestation of such norms is far from being completed, with the Anti-homosexuality Bill having been repealed by the Constitutional Court. This illustrates the fact that LGBTI organisations in Uganda have managed a level of influence on the diffusion of human rights norms affecting the population they represent which CBOs in Honduras or Ukraine had been unable to reach.

¹³⁸ Interview with Leonard Okello, HIV activist, Kampala, 23 April 2013.

¹³⁹ Interview with an activist at Health Gap, Kampala, 21 April 2013.

¹⁴⁰ See for example: Amnesty International, ‘Uganda: Anti-homosexuality Act prompts arrests, attacks, evictions, flight’, 15 May 2014; AFP, ‘Uganda shelves controversial anti-gay bill’, 13 May 2011;

¹⁴¹ UN Secretary-General's speech at event on “Ending Violence and Criminal Sanctions Based on Sexual Orientation and Gender Identity”, New York, 10 December 2010.

The mitigated response of outsider proponents of HIV norms

Global HIV/AIDS governance institutions are unequivocal about the consideration of legislation criminalising homosexuality as a factor which both causes and boosts the rate of HIV infection among MSM. The International Commission on HIV and the Law states that: “...there is growing international consensus that the decriminalisation of homosexuality is an essential component of a comprehensive public health response to the elevated risk of HIV acquisition and transmission among men who have sex with men” (UNDP, 2012:48). By contrast, evidence shows that in a range of epidemic settings, universal access to HIV services for MSM together with anti-discrimination efforts can significantly reduce infections both among those men and the wider community (UNAIDS, 2009; Beyrer et al., 2011). Global HIV/AIDS governance and policies have played a crucial, but mitigated role in introducing targeted programmes for MSM into the diffusion of international HIV norms and has facilitated the penetration of LGBTI rights discourse in Africa (Amory, 1997).

However, this penetration has been markedly slow in Uganda, even in securing the adequate provision of HIV and other health services to LGBTI people. HIV norms underpin the strong correlation between criminalisation and under-investment in HIV services for MSM (AMFAR, 2012). This is partly because these laws make it politically difficult for governments to justify the necessary funding for providing HIV support (Beyrer, 2010). Such was the case of Uganda. As late as March 2008, the Special Rapporteur on the Right to Health expressed concern that the government’s health policy was not rights-based, and did not give sufficient attention to the right to health of some vulnerable groups such as MSM.¹⁴² The proportion of HIV prevention expenditure devoted to programmes for sex workers and their clients, MSM and people who inject drugs in Uganda was reportedly only 0.2% as late as 2012.¹⁴³

The fact that the domestic response to HIV among MSM and transgender people in Uganda was so inadequate up until well into the 2010s, even when it has always been almost entirely driven by international donors, shows the great extent of the interference of political and diplomatic implications of the homosexuality debate into the diffusion of HIV norms in Uganda. In a country where HIV has had such a devastating impact, the epidemic is a serious political and economic issue, attracting over £300 million yearly of direct international donor

¹⁴² Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, Paul Hunt, Addendum.2, UN Doc: A/HRC/7/11.Add.2, 5 March 2008.

¹⁴³ IHAA, ‘Take a stand against homophobic media in Uganda’, <http://www.aidsalliance.org/includes/document/UgandaReadMore.pdf>. Accessed on 9 March 2013.

funding (over 83% of which is from the US Government's PEPFAR) and is still being coordinated by the Uganda HIV and AIDS Commission, which reports directly to the President's Office (Uganda AIDS Commission, 2012).¹⁴⁴

It is evident that the political dimensions of the Anti-homosexuality Bill, which generated such outspoken condemnation by governments the world over did not affect the funding of the national HIV response in Uganda until much later, when it was clear that by excluding the LGBTI community, Uganda's HIV/AIDS response was falling seriously short in curbing the epidemic.¹⁴⁵ It was only in 2012 that some bilateral funding (from the Danish development agency, DANIDA) began to flow directly to HIV services provided by the LGBTI CBOs for MSM and transgender people studied in this chapter (mainly SMUG, and Ice Breakers) and the Global Fund disbursed funding for such services to both civil society and government. Both programmes however kept a low profile at request of donors themselves, so to avoid further confrontation with the Ugandan authorities.¹⁴⁶

The revived interest by donors as outsider proponents of HIV norms as regards to MSM is having a marked influence on the strategies of the LGBTI groups studied. Ironically, the severity of the HIV epidemic in Uganda and the failure of the Ugandan authorities to respond to it in the past few years, has kept the public health debate alive. It has contributed to LGBTI groups gaining agency to influence the diffusion of HIV norms even when the larger political space and human rights norm diffusion remained closed to them. From this point of view, the relationship between the implementation of international HIV/AIDS norms and the implementation of international human rights norms LGBTI people in Uganda has come full circle.¹⁴⁷

Conclusion

The LGBTI organisations studied in this chapter have gained considerably higher influence on the diffusion of international norms than organisations in the previous cases of Honduras and Ukraine. The Ugandan CBOs analysed managed to gain sufficient agency among the judiciary to halt, at least momentarily, the contestation by state actors at the highest hierarchical level of

¹⁴⁴ Interview with Enid Wamami, Director of Partnerships, Uganda AIDS Commission, Kampala, 19 April 2013.

¹⁴⁵ Interview with an activist from Health Gap, Kampala, 21 April 2013.

¹⁴⁶ Interview with Sanne Frost Health, Counsellor, Human Development Team, DANIDA, Danish Embassy, Kampala, 17 April 2013.

¹⁴⁷ Interview with a representative from Community Health Alliance Uganda, Kampala, 16 April 2013.

human right norms pertaining to the protection of people on grounds of sexual orientation or gender identity. This influence was lacking in the cases of Honduras and Ukraine. In spite of a context of wide rejection of sexual minorities among internal actors, including most state structures, the LGBTI organisations studied in Uganda found among external actors (donor governments and international human rights NGOs particularly) key allies to oppose this contestation, favouring a stand-off between Ugandan norms takers and these actors which is far from resolved. In this respect, this case study illustrates well the concept of ‘boomerang effects’ within norm diffusion, whereby even when states choose to contest or reject a norm, other agents within the jurisdiction of these states can connect with outsider proponents, including states and TANs advocating for a particular norm, to persuade or force the state in question to reconsider their previously stated position (Keck and Sikkink, 1998; Hertel, 2006).

Much as in the case of CBOs in Honduras and Ukraine, the assimilation of international norms is a critical strategy of the LGBTI organisations studied in Uganda. This case study shows how tactical and adaptable to the external context such appropriation is. Whilst the CBOs studied in Ukraine mostly focus on owning human rights-based HIV norms leveraging their position as implementers of harm reduction programmes, Ugandan LGBTI organisations have mostly embraced international human rights norms (like in the case of transgender organisations in Honduras) and used HIV/AIDS governance less frequently as a reaction of changes in HIV policies in Uganda and as a consequence of the little role they have been given in the implementation of such policies until very recently. Over the past years though, LGBTI organisations have contributed to the domestic response to HIV, providing HIV services through their own local practice, and lately, in collaboration with the Ministry of Health, as part of the national response to the epidemic.

Two relevant findings of this case study contribute to explaining this dynamic appropriation of norms. First, the global constructs associated with the application of human rights norms to fight discrimination based on sexual orientation and gender identity means that the CBOs analysed need to play more of a vernacular role among the population they represent than in the previous case study. Second, given the Ugandan socio-political context, these CBOs need to carefully balance the dilemma between resonating among their members by localising these international norms so that they fit in the local context whilst attracting external actors who champion these global constructs (Levitt and Merry, 2009). The behaviour of these external actors offers a significant contribution of this chapter to norm theory. On top of showcasing the inconsistency of states’ behaviour in relation to opposing norm diffusion processes also

described in the case of Ukraine, this case study demonstrates that external actors can also show inconsistent positions in relation to opposing norm diffusion processes in a given country exposing contradicting positions among their representatives in the various governance systems where these processes take place.

Crucially, the case study begins to describe how the CBOs analysed leverage one norm diffusion process to affect another. The considerable agency gained by the Ugandan LGBTI organisations studied within the human rights governance is overwhelmingly due to influence these organisations have had among external actors in the face of almost total rejection among internal actors, including most political, social and religious leaders. The determination with which many state representatives manifest this rejection testifies to the role of national leadership not just in localising (or *glocalising*) international norms (Brown, 2014) but also in contesting these norms beyond the normative field on to the political and diplomatic arenas. However, the agency of the CBOs studied among external actors has eventually opened some space for these organisations to reach out to state representatives, such as the Ministry of Health and external actors within the HIV/AIDS governance (such as bilateral and multilateral HIV donors and international HIV and Health NGOs) to begin to infuse human rights principles into the diffusion of HIV norms in Uganda.

The next case study on CBOs people living with HIV will describe how the organisation studied in El Salvador leverage their position in relation to various governance systems, and the strategies they used to influence the most relevant state actors and key non-state internal actors such as the media and mainstream civil society movements to the point of making key state representatives reverse on their own positions in relation to international human rights norms.

7. REVERSING CONTESTATION: PEOPLE LIVING WITH HIV IN EL SALVADOR

Introduction

This case study describes a maximum level of influence on the diffusion of international norms among all the CBO analysed in the empirical chapters. The CBOs of people living with HIV studied in El Salvador persuaded the government not only to adopt both human rights and HIV norms regarding universal and free access to ARV treatment for people living with HIV, which it had previously rejected, but also to become a resolute international champion of such norms long before they were introduced in other countries. Such influence demonstrates that states can indeed reverse their positions in relation to international norms over time even after they have contested or modified them (Acharya, 2004). The case study demonstrates that such change in government positions can take place towards the later part of the norm diffusion process through the action of local non-state actors, such as CBOs, and not just at the earlier stage of norm socialisation, when external actors (for example international NGOs or donors) interact with states (Keck and Sikkink, 1998; Finnemore and Sikkink, 1998).

Unlike all previous cases studied in this thesis, the organisations of people living with HIV studied in El Salvador obtained ample support among internal actors, including influential political and social actors (such as the medical trade union) and the media. More importantly, these CBOs managed to influence representatives of the state at the highest level of hierarchies even when for a long period of time they had been unable to do so with health authorities. This is the opposite case to Ukraine and Honduras. This circumstance underpins the importance of understanding hierarchies in states structures to be able to analyse how international norms compete with each other and the role national leadership and hierarchies play in such competition (Snow et al., 1986; Tarrow, 2005; Brown, 2014).

The CBOs studied in El Salvador, in particular Atlacatl, also managed to leverage their influence on the regional (Inter-American) human rights system to influence norm diffusion processes within national HIV/AIDS governance. The case of El Salvador in this respect contributes to norm diffusion theory revealing the importance of hierarchies among external actors across various international norms governance systems (Keck and Sikkink, 1998; Hertel, 2006). The international and regional human rights systems include a variety of compliance mechanisms, including treaty bodies, international/regional human rights courts and commissions which global HIV governance lacks. By presenting their case to the Inter-American

Commission of Human Rights (IACHR), the CBOs analysed influenced an external actor at the higher level of hierarchy in the human rights system, with the power to influence the positions of governments not only around human rights, but also in HIV/AIDS governance.

Finally, the case study challenges the advocacy and resonance dilemmas described by Lewitt and Merry when referring to the limitations of organisations to act as vernacularisers of international norms (Lewitt and Merry, 2009). The CBOs of people living with HIV studied in El Salvador advocated for the right to access ARV treatment, which represented a major challenge to the status quo at a time when that norm was not even widely adopted by states worldwide, influencing a government which had resolutely opposed it. The norm resonated strongly among CBO members, who were dying of AIDS in numbers and for whom any other more acceptable alternative for the local political context was simply not an option.

Context: the HIV and AIDS response in El Salvador since 2000

The first case of AIDS in El Salvador was diagnosed in 1984. In 2010 there were an estimated 30,000 people living with HIV. Around 82% of registered cases currently correspond to people aged between 15 and 49. Around 48% of people living with HIV in El Salvador live in poverty (UNDP and Ministry of Health of El Salvador, 2010). Sexual intercourse is the main mode of HIV transmission, representing 93% of cases. Although the epidemic is highly concentrated among MSM, the percentage of homosexual transmission is unknown since very few MSM would report having homosexual practices when testing fearing stigma and discrimination.¹⁴⁸ Around 0.8% of adults are currently living with HIV. The number of infected people has risen by around 10% year-on-year since 2004, and the ratio of women to men has increased (*Programa Nacional*, 2009).

In the late 1990s, Odir Miranda (Miranda) and a group of other people living with HIV (later to become the organisation *Atlatl Vivo Positivo*, *Atlatl*) took cases first before the national judicial bodies and then before the Inter-American ones, and undertook high profile communications campaigning and street mobilisation. El Salvador was the first state to be taken to the Inter American Commission on Human Rights (IACHR) for not providing free treatment to people living with HIV. The case became a world reference for people living with HIV and paved the way to ensure that El Salvador and other countries in Central America provided free HIV treatment. In 2000, the first limited distribution of ARVs through the *Instituto*

¹⁴⁸ Interview with Odir Miranda, Director of *Atlatl*, San Salvador, 4 October 2012.

del Seguro Social de El Salvador, ISSS (Salvadoran Social Security Institute) started and from 2004, it was made available through the national public health system.¹⁴⁹ The country relies heavily on international donors, especially the Global Fund. The majority of civil society organisations working on HIV receive funding from the Global Fund or other international donors, although the most representative organisations of people living with HIV get a small annual grant from the state (as of 2012, around US\$ 25,000 a year). The Global Fund is planning to exit the country in the coming years. This will put considerable pressure on the government to finance HIV services.¹⁵⁰

People living with HIV: from patients to human rights activists

This section describes the development of Atlacatl, the most prominent organisation of people living with HIV in El Salvador over the past 15 years. Atlacatl has evolved from being an AIDS patient support group (*Grupo de Apoyo*) to an NGO mostly focused on HIV prevention and advocacy. During the timeframe this case study mostly covers (2000-2010), Atlacatl was solely formed of volunteers living with HIV, with a board also formed of volunteers living with HIV. Most of its first members died of AIDS before ARVs were widely accessible. Although the vast majority of members were gay men, membership included representatives from a wide range of subpopulations living with HIV, including other members of the LGBTI population and heterosexual people with diverse social and economic status.

Embracing of international human rights norms was the single most important element in the creation of Atlacatl as an organisation since it was the case for the provision of ARVs presented to the IACHR by Miranda, co-founder of Atlacatl, which led to the formation of the group.¹⁵¹ The case itself describes the international norms Atlacatl and its members owned and claimed.¹⁵² These norms are part of the Inter-American human rights system (see later in this chapter) but mirror widely diffused international human rights norms in legal standards that El Salvador has ratified,¹⁵³ the most relevant of them all being Article 12 of the ICESCR, which states the “right of everyone to the enjoyment of the highest attainable standard of physical

¹⁴⁹ Interview with Ana Nieto, Head of the *Programa Nacional de ITS/VIH-SIDA* Ministerio de Salud Pública y Asistencia Social (National HIV Programme), San Salvador, 1 October 2012.

¹⁵⁰ Interview with Ana Nieto, Head of the *Programa Nacional de ITS/VIH-SIDA* Ministerio de Salud Pública y Asistencia Social (National HIV Programme), San Salvador, 1 October 2012.

¹⁵¹ Interview with Jaime Argueta, Director of the HIV unit, *Procuraduría* of Human Rights, San Salvador, 5 October 2012.

¹⁵² Interview with Odir Miranda, Director of Atlacatl, San Salvador, 4 October 2012.

¹⁵³ Interview with Oscar Humberto Luna, *Procurador* of Human Rights of El Salvador, San Salvador, 9 October 2012.

and mental health” whilst recognising that this standard is to be progressively realised within the state’s resources (see Appendix 3).¹⁵⁴ However, access to essential medicines is a core minimum obligation of states under the Covenant, taking immediate effect (UNCESCR 1990, 2000). The group and organisations of people living with HIV in other countries considered that ARVs, the only treatment able to save the lives of people living with HIV, should be considered essential medicines (Kavanagh et al., 2015).¹⁵⁵

The development of Atlacatl in the early days benefited from a social and political period of transition with a myriad of organisations and institutions promoting human rights norms, including NGOs, unions and others, some of which constituted allies for the CBO. Although the support Atlacatl received from internal actors was not as comprehensive as, for instance, organisations of people living with HIV in Brazil, which involved a therapeutic mobilisation across a great portion of society (Biehl, 2012), the critical role of this support underpins the importance that some authors give to internal non-state actors including local elites, NGOs or other active civil society groups in advocating to state representatives for the adoption or rejection of particular international norms (Nadelmann, 1990; Acharya, 2004; Kravtsov, 2009).

The early poor norm appropriation among people living with HIV

In the early stages in the development of organisations of people living with HIV in El Salvador until the early 2000s, when HIV treatment started to be available in the country, people diagnosed with HIV had very little prospect of survival beyond a few months. Combination treatment (cocktails of medicines that when combined make a significant difference in patients’ outcomes) was available in the US, Costa Rica, and Brazil but not in El Salvador. Only a few people with economic means were able to access it privately or abroad.¹⁵⁶ Through the national public health system, doctors were only able to provide treatment for opportunistic diseases associated with HIV/AIDS, and patients were referred to *grupos de apoyo* (support groups), usually associated to hospitals, where they received psychosocial counselling and a safe space to talk to each other about their condition.¹⁵⁷ These groups are similar to the *casas*

¹⁵⁴ Ratified by El Salvador in 1979, United Nations Treaty Collection, <https://treaties.un.org>. Accessed on 16 June 2015.

¹⁵⁵ Interview with Odir Miranda, Director of Atlacatl, San Salvador, 4 October 2012.

¹⁵⁶ Interview with Dr Jorge Panameño, infectologist, San Salvador, 8 October 2012.

¹⁵⁷ Public health care in El Salvador is provided by the *Instituto del Seguro Social de El Salvador* (ISSS), to which employed people contribute a portion of their salaries (around 15-18% of the population); the National Public Health Care service, for unemployed or those working in the informal sector (around 80%); and the Military Health

de apoio (support shelters) described by Biehl in Brazil, although they focused more on an economy of survival in terms of housing and food, rather than treatment adherence, since access to treatment was not provided as in the case of Brazil (Biehl, 2007).

*I was diagnosed with HIV in 1996, at the time, that was a death sentence. They referred me to the support group at the hospital. At first I didn't want to go, there were all sorts of people there; I had nothing to do with them. But I had nowhere else to go. I think there are two or three still alive from that group.*¹⁵⁸

There are various views as to what the character of the mobilisation of people of living with HIV was in its origin. For the majority of people living with HIV at the time who are still alive, it was a matter of survival rather than demanding human rights per se. The vast majority of people living with HIV and the organisations representing them had not embraced human rights to the point of organising around them.¹⁵⁹

*When I was diagnosed, I was given a 3-month lifespan prognosis. There was no hope. I resorted to religious sects, I told my family and friends because I knew they were as promiscuous as I had been. I had to tell my wife and girls, I went back to all lovers I had had to tell them. It was really hard. Many abandoned me, the last thing around me was solidarity, and the last thing in my mind was to try to find help to mobilise and claim our rights and access to treatment. That wasn't the time for solidarity, if anything it was the time for pity.*¹⁶⁰

There are three main reasons that explain this phenomenon: fear of taking on the government as a long legacy of conflict and oppressive governments; fear of 'coming out' as people living with HIV with the prospect of facing public rejection and stigma; and the lack of a structured network of active organisations of people living with HIV since the only existing groups were support groups in hospitals, the aim of which was to provide peer-to-peer psychosocial support, not to mount campaigns or claim their rights.

I was diagnosed with HIV in 1997. My doctor put me in contact with a support group there. For me that was more moral support than anything. Then I joined the street demonstrations. I always covered my face in these demonstrations. I was afraid of

service, for servicemen and women (representing around 5-2% of the population).

¹⁵⁸ Interview with a person living with HIV, San Salvador, 4 October 2012.

¹⁵⁹ Interviews with people living with HIV, San Salvador, 1-4 October 2012.

¹⁶⁰ Interview with a female person living with HIV, San Salvador, 1 October 2012.

people knowing. I joined Odir [Miranda] with those who took on the government, but my name was never made public. At the school where I used to teach, the headmistress knows my HIV positive status, but parents don't. I can't teach children anymore, they've given me a job making decorations for the schoolrooms and school celebrations.¹⁶¹

At the time, the national HIV response was submerged in a context of therapeutic sovereignty, similar to the description Nguyen gives about West Africa, whereby doctors decided who was to receive treatment when it was not yet widely available (Nguyen, 2010). For some people living with HIV at the time, these were arbitrary, based on whether the patient was perceived as been a 'good person,' or 'not too promiscuous', and they felt that women and heterosexual men had a priority for treatment, irrespective of how urgently they needed treatment.¹⁶²

When I was in hospital, I just didn't pay attention to the red bag hanging at the edge of the bed. That bag meant that I was HIV positive and everybody would know that. The nurses avoided coming to me as much as they could, people next to me asked to be transferred to another room. When I sat at a chair in the corridor, somebody would come to clean the chair after me. I just saw it as normal, my family and I thought it was what I deserved. It is when I got access to treatment and I started to feel stronger, more as a human, when I realised I had rights like anybody else. It is really difficult to claim your rights when you feel ill and weak.¹⁶³

The support groups brought a circle of solidarity and closeness between people who otherwise would have not interacted at all. Nguyen's concept of moral economy developed among people living with HIV can be attributed to this solidarity, at least in two key characteristics of such concept: trust and social belonging (Nguyen, 2010).

I used to watch Odir [Miranda], Otoniel, and other activists living with HIV on the television. I remember thinking that somehow they were people who had done something wrong. I am a housewife and at the time I was very religious. When I knew I was HIV positive, I started to go to the support groups. There I met people I would have never met, like gay men and transgender women. We were brothers and sisters, we all

¹⁶¹ Interview with a female person living with HIV, San Salvador, 1 October 2012.

¹⁶² Interview with Jaime Argueta, Director of the HIV unit, *Procaduría* of Human Rights, San Salvador, 5 October 2012.

¹⁶³ Interview with Jaime Argueta, Director of the HIV unit, *Procaduría* of Human Rights, San Salvador, 5 October 2012.

*were sharing our condition and nobody felt really different. And this is like this now, they are my best friends.*¹⁶⁴

The lack of organisational structures made of and for the rights of people living with HIV was common to many countries until it was discovered that the right combination of drugs could have a significant impact on the outcome of people with AIDS, improving their quality of life dramatically, and extending their life-expectancy to the point of turning a fatal condition into a chronic one.¹⁶⁵ The decision by the government to render ARVs accessible to all people living with HIV in the mid-2000s would allow many of these people to shift from a survival mind-set to one seeking social acceptance, and for some, the realisation that they were entitled to human rights. Empowered by the sense of solidarity and identification described earlier, many support groups became CBOs involved in the HIV response.¹⁶⁶

Social conflict and the mobilisation of internal human rights champions

The social and political context where CBOs of people living with HIV starting to mobilise highlights the important role that internal non state actors can have in the diffusion of norms to the national level thought the influence they can have on the government and other relevant state actors (Checkel, 1998; Gurowitz, 1999; Farrell, 2001). The internal political context and civil society human rights champions played a crucial role in the support that, eventually, CBOs of people living with HIV obtained to be able to access ARVs. A first key internal ally with influence on wider society was *the Sindicato de Médicos Trabajadores del Instituto Salvadoreño del Seguro Social*, SIMETRIS, the first medical doctors' union in El Salvador.

The human rights context in the 1990s was marked by a long history of political repression by successive military-influenced governments and a heavily politicised society after a 12-year civil war, which ended in 1992. Human rights remained a high profile political issue often linked back to grievances related to the behaviour of the parties to the conflict (Miller, 2004). All this was closely monitored by both other Central American states, whose respective internal conflicts had ramifications from and to the El Salvadoran conflict; and the international community, especially the United States, with strong interest in the area (Call, 2003).¹⁶⁷

¹⁶⁴ Interview with a person living with HIV, San Salvador 6 October 2012.

¹⁶⁵ Interview with Dr Rodrigo Simán, former Head of the HIV Programme, Ministry of Health, San Salvador, 1 October 2012.

¹⁶⁶ Interview with a person living with HIV who was among those who sued the El Salvador government, San Salvador, 1 October 2012.

¹⁶⁷ Interview with Oscar Humberto Luna, *Procurador* of Human Rights of El Salvador, San Salvador, 9 October 2012.

Towards the end of 1990s, embryonic civil society organisations started to emerge as advocates of human rights and equality norms and as an opposition to conservative norm takers and tight economic structural adjustments perceived as imposed by the World Bank and other international monetary institutions (Castillo, 2001).

A key battleground on the economic front were perceived inequalities in the provision of public health, with only 14% of the population accessing quality public services under the ISSS, and plans by the conservative ARENA government to privatise the entire provision of health services. The public health care doctors who created SIMETRISSS were fiercely opposed to the privatisation of the public health service as they considered that it would deepen inequalities in access to health. From 1998, SIMETRISSS called for strikes and other industrial actions to revert privatisation plans, which culminated in a one-year strike in 2003.¹⁶⁸

By the mid-1990s, it was evident to doctors working with HIV patients that the HIV epidemic was spreading fast. Some of these doctors had seen the positive impact of ARVs in patients' outcomes abroad, while in El Salvador, most patients did not have access to ARVs and were just treated for opportunistic diseases. For Dr Jorge Panameño, one of the key leaders in SIMETRISSS and for other doctors looking after HIV patients in public hospitals, the lack of treatment for HIV patients and the growing impact of HIV illustrated like no other the inner arguments for SIMETRISSS' mobilisation to strengthen the public health system. SIMETRISSS would be critical in the transformation of a support group of people living with HIV into the CBO who sued the state at the IACHR (see later in this chapter). Neither the CBOs studied in Honduras, Ukraine nor Uganda were able to attract national forces with that degree of popular support and political influence.

I was one of Dr. Panameño's patients. He gave me some expired medication that he got from the US, and I got better. We talked a lot about our respective struggles, and we saw that there our fight of SIMETRISSS was one for the people with HIV too. He told me you have to be bold, campaign, do a march with fake coffins in front of the ministry (of health).¹⁶⁹

However, the social consideration of AIDS at that time was extremely negative. AIDS was widely referred to as the Pink Plague. The military and the police often harassed sexual minorities perceived as carrying the virus. This intimidation was a reminiscent of the civil war,

¹⁶⁸ Interview with Dr Jorge Panameño, infectologist, San Salvador, 8 October 2012.

¹⁶⁹ Interview with Odir Miranda, Director of Atlacatl, San Salvador, 4 October 2012.

where moral and religious judgements were forcibly acted upon by law enforcement officers with virtually total impunity, and flourished among total lack of tradition of civil society mobilisation or protest after years of civil war. This meant that, although the social context of El Salvador was conducive for the demands of people living with HIV, Atlacatl and other CBOs had to lay down specific strategies to attract internal actors, which are discussed later in this chapter.¹⁷⁰

CBOs' strategic shift: influencing the diffusion of human rights norms

The change in the nature of CBOs of people living with HIV from patients to activists in the late 1990s marks the beginning of a strategy to try to influence the government, who rejected the notion that the universal and free provision of ARVs was a human rights imperative of the right to health enshrined in international human rights norms ratified by El Salvador. From the point of view of norm diffusion theory, this case study demonstrates that changes in states' positions regarding international norms can take place towards the later part of the norm diffusion process, when the norms must enter national practice, and not only at the earlier stage of international level of socialisation (Keck and Sikkink, 1998; Finnemore and Sikkink, 1998).

CBOs in El Salvador gained influence among both external and internal actors contemporarily and not just external actors (as was the case of Ukraine and Uganda). In the context of increased civil society mobilisation around human rights in the late 1990s, the landscape of poor awareness of human rights by people living with HIV changed considerably. In 1998, Miranda and other people living with HIV who did not want to make their names public, began to campaign to access ARVs under the generic name of *Grupo de Pacientes con VIH del Seguro Social*, (Group of HIV Patients of ISSS, later to become Atlacatl). The group was supported by SIMETRIS and other political and social forces. It also attracted wide support from the media. Although a large number of members of the support group, including its leader, Miranda, were members of the LGBTI population, the group took the decision not to advocate for LGBTI rights but to focus on access to HIV. This is a significant departure from many other CBOs of people living with HIV campaigning at that time in other countries, including Brazil where the LGBTI and HIV movements were completely integrated (Biehl, 2007). This strategy aimed to gain the widest popular support possible, even among homophobic sectors of society, mainly through the mainstream media, in contrast with overwhelmingly hostile media environment CBOs in Uganda and Ukraine endured.

¹⁷⁰ Interview with Francisco Ortiz, Director of Fundasida for people living with HIV, San Salvador, 9 October 2012.

*We mounted a media campaign, invited the papers to come see me in my dying bed in hospital. The story wasn't about me being gay, it was about somebody who should get his medicines and get better, not die. I was all over the press, and got thousands of letters of support.*¹⁷¹

Externally, instead of only engaging with international NGOs, the group engaged with the IACHR, a formal norm compliance mechanism, taking advantage of the robust human rights governance structures that the Inter American system had created. Later in 1998 the group presented the first draft HIV law to the Legislative Assembly and requested antiretroviral medication from the public health authorities.

*At the time, I just thought I didn't need psychological support or help to die in dignity. I wanted to live and I thought the state had to provide for my health.*¹⁷²

The first step the group took was an administrative request for the ISSS to provide ARVs. In reality, it represented the first attempt by an emerging CBO of people living with HIV to influence the diffusion of HIV norms in El Salvador. This first move focused on influencing the health authorities using their own processes. The ISSS rejected the request arguing lack of available funding. On 28 April 1998, Miranda filed a petition before the Supreme Court of El Salvador. This second step meant the involvement of the judiciary, another key state structure. Already this early on, Miranda and others framed their demands on health-related issues such as the provision of ARVs around principles enshrined in international human rights norms as Miranda took the ISSS to court for violation of the rights to life and health, and for infringement of the principle of equality.¹⁷³

By the end of 1999, the Supreme Court was still to take a decision on the case but the groups' strategies towards internal actors were taking shape. First, unlike most early movements demanding treatment in Brazil and across Africa, the El Salvador movement drew wide sympathetic media coverage for a particular individual who, from his sickbed, was demanding that the state save his life.¹⁷⁴ The movement of people living with HIV eventually became the public face of the wider struggle for a fairer health system, taking the pressure the

¹⁷¹ Interview with Odir Miranda, Director of Atlacatl, San Salvador, 4 October 2012.

¹⁷² Interview with Odir Miranda, Director of Atlacatl, San Salvador, 4 October 2012.

¹⁷³ Interview with Odir Miranda, Director of Atlacatl, San Salvador, 4 October 2012.

¹⁷⁴ Interview with Sergio Montealegre, Coordinator of REDCA+, Central American Network of People Living with HIV. San Salvador, 1 October 2012.

government was under to a different level.¹⁷⁵ Then, the group also utilised internal human rights and equality champions, doctors in particular. When the Group of HIV Patients of the ISSS, was created, the Medical Association SIMETRISSS saw in it a first serious attempt to mobilise against the powers that be. For most doctors, the state was violating the human right to health of people living with HIV by not providing free ARV treatment.¹⁷⁶ In turn, the group's first manifesto expressed its solidarity with the SIMETRISSS for opposing the privatisation of the provision of health.¹⁷⁷ Miranda and other people living with HIV were appealed simultaneously to the government and the judiciary and to key internal non-state attracting wide public sympathy. CBOs in Honduras, Ukraine and Uganda were unable to do so.

On 24 January 2000, with the ISSS still refusing to provide antiretroviral treatment, a larger group of 27 people living with HIV, including Miranda, took the situation to the regional arena, presenting a petition to the IACHR accusing the state of violating the rights to life; to humane treatment, to equal protection of the law, to judicial protection, and to economic, social and cultural rights as stated by the American Convention on Human Rights and other international human rights treaties signed and ratified by the Republic of El Salvador (IACHR, 2009).¹⁷⁸ The petitioners alleged that the state violated their right to life, health and well-being "inasmuch it [had] not provided them with the triple therapy medication needed to prevent them from dying and improve their quality of life" (IACHR, 2009: 1). This was the first ever case on the right to health at the IACHR, marking a significant qualitative change in the organisation's strategies. The CBO appealed to a key regional human rights body to influence the diffusion of international HIV norms into El Salvador, effectively, trying to persuade an external actor in one governance system (human rights) to influence another governance system (HIV/AIDS).

Two weeks after the presentation of the complaint, the Commission dictated Precautionary Measures. The Measures demanded that the government provide ARVS to all 27 plaintiffs with immediate effect (IACHR, 2009). On 4 April 2001, the Supreme Court of El Salvador ruled that the El Salvadoran Constitution had been violated and ordered the therapy to be provided to Miranda, but it did not extend the ruling to other persons living with HIV as requested. The petitioners still held the view that the delay in taking the decision constituted a

¹⁷⁵ Interview with Dr Jorge Panameño, infectologist, San Salvador, 8 October 2012.

¹⁷⁶ Interview with Dr Jorge Panameño, infectologist, San Salvador, 8 October 2012.

¹⁷⁷ Interview with Odir Miranda, Director of Atlacatl, San Salvador, 4 October 2012.

¹⁷⁸ Articles 4, 5, 24, 25, and 26.

further violation of the right to fair trial and judicial protection (IACHR, 2009). In November 2004, the IACHR made its report public to the parties. The decision shows how far a CBO of people living with HIV had gone in influencing the diffusion international norms under both the international (regional) human rights system and the HIV/AIDS governance.

The Commission concluded that the state violated several provisions of the American Convention on Human Rights: article 2, (adoption of legal provisions to guarantee the rights enshrined in the convention) and article 25 (right to effective judicial protection) as regards to all petitioners; and article 24 (right to equal protection of the law) in the case of Miranda. The Commission indicated that the state had not violated article 26 (economic, social and cultural rights), and did not render any decision on article 4 (right to life) or Article 5 (right to humane treatment) because of “the subsidiary nature of the corresponding arguments in this case”.

The Commission recommended that legislative measures be implemented to amend national provisions to make them simple, prompt and effective, and that reparation be provided to the 27 plaintiffs for the human rights violations found (IACHR, 2009). Parallel to the process at the IACHR, negotiations between the Government and Group of HIV Patients of ISSS took place. They lasted from 2001 to 2007, when both parties reached a Friendly Settlement. The settlement established mainly: the inauguration of a Solidarity Garden; US \$2,000 compensation for each plaintiff; a new law of constitutional procedures, an annual public ceremony of recognition and solidarity; and an annual grant for organisations of people living with HIV (IACHR, 2009).

Actors in global HIV/AIDS governance: from disregard to appropriation

Unlike in the case of organisations of people who use drugs in Ukraine but much like in the cases of Honduras and Uganda, the CBOs of people living with HIV studied in El Salvador found it hard to rally HIV donors behind their attempts to influence the government, especially at the beginning of their mobilisation. The minimal role that international funders played in the demands of people living with HIV around access to treatment in the early 2000s was deeply criticised among civil society actors and other internal actors.¹⁷⁹ The erratic behaviour of external actors in the HIV response in El Salvador adds another layer to the study of the contradictions among external actors operating in various governance systems described in the previous case studies. This case reveals how although at the international level some actors can

¹⁷⁹ Interview with Dr Rodrigo Simán, former Head of the HIV Programme, Minister of Health, San Salvador, 1 October 2012.

have clearly defined policies regarding norms, for instance UNAIDS being a champion of universal access to ARVs as a key human rights-based HIV norm, the behaviour of representatives of such actors can be very different at the local level (for example, UNAIDS country coordinators) as a result of their interaction with government officials, national leadership and other internal actors.

From the very outset of the mobilisation for ARVs in El Salvador, the few UN agencies present in the country, namely UNAIDS and the UN Development Programme (UNDP), and international donors, such as USAID through its Program for Strengthening the Central American Response to HIV/AIDS (PASCA), questioned the position of people living with HIV who were demanding free access to treatment on the grounds of cost implications.¹⁸⁰ Some agencies and international NGOs supporting the in-country response at the time, including HIVOS (which later on changed its approach), the Dutch Government, and Christian Aid, only provided funding for palliative support and care and did not support the mobilisation of people living with HIV to obtain treatment.

*I remember a conversation with the representative of HIVOS at the beginning of our mobilisation. They said that they had heard that the group was only looking for treatment. I replied, "if you think that treatment is not important, I don't understand how you are planning to support us". They ended up giving our group the first grant we ever had. It was focused to claiming our rights, starting with the right to treatment.*¹⁸¹

Later on, when the government announced the free provision of ARVs, international donors started to fund treatment, focusing almost exclusively on testing and delivering, not on monitoring adherence by patients to their treatment.¹⁸² During the first few years of ARV provision (2002-5 approximately), the main prevention strategy by government and donors was to get people living with HIV to go public with their stories. Organisations would pay for people to give their testimony in workshops, conferences, and the media in a ritual repeated around the world which Nguyen refers to as confessional technologies (Nguyen, 2010).¹⁸³

¹⁸⁰ Interview with Odir Miranda, Director of Atlacatl, San Salvador, 4 October 2012.

¹⁸¹ Interview with Odir Miranda, Director of Atlacatl, San Salvador, 4 October 2012.

¹⁸² Interview with Sergio Montealegre, Coordinator of REDCA+, Central American Network of People Living with HIV. San Salvador, 1 October 2012.

¹⁸³ Interview with Jaime Argueta, Director of the HIV unit, *Procaduría* of Human Rights, San Salvador, 5 October 2012.

Around 2003, the organisations and funders, like Plan International, the Ministry of Health or Fundasida, always finished their workshops with the testimony of someone living with HIV. They often called me to talk; they would pay me for it, US \$10-20 per session. It was like my job, because at the time very few people living with HIV wanted to talk, so they kept asking me. Nobody would see me as a professional, but as a 'talking head'. I had to tell my personal story and urge people protect yourselves so that you don't live what I live, It wasn't about asking people to do the test because if you are HIV positive you will be provided treatment and they will care for you. It was a total re-victimisation process, but I didn't see like that at the time, I felt important. When I started to talk beyond the victim story, they looked for somebody else who would say 'poor me, I am HIV positive'.¹⁸⁴

A key factor to explain the mitigated role of donors and UN agencies once ARV was available is that many of these actors aligned with the government rather than challenging its refusal to implement a national response to HIV response based on human rights.¹⁸⁵ This politicisation of UN agencies might have compromised their legitimacy to promote the human rights of people affected by HIV and limited the support they provide to NGOs working in the area of HIV and human rights.¹⁸⁶ For instance, Hebert Betancour was Deputy Minister and then Minister of Health under the previous government at the time when ARVs were denied to people living with HIV. A few years later he was in charge of the UN contribution to the HIV response in El Salvador, as UNAIDS Country Coordinator. This shows how tenuous the distinction between the domestic branches of international organisations and state structures can potentially be.

On occasions, UN agencies have actually acted as human right norm opponents rather than champions, reflecting the highly politicised context of the HIV response in El Salvador. For instance, in the course of an investigation on stigma being carried out with UNDP funding in 2009, the Demographic Association of EL Salvador (*Asociación Democrática Salvadoreña, ADS*) and *Vida Nueva*, an organisation of people living with HIV, found that a national maternal hospital undertook forced-sterilisation procedures on women living with HIV between 2008 and 2009. The report stated that "7.6% [of HIV positive pregnant women] reported coercion

¹⁸⁴ Interview with Jaime Argueta, Director of the HIV unit, *Procuraduría* of Human Rights, San Salvador, 5 October 2012.

¹⁸⁵ Interview with Odir Miranda, Director of Atlacatl, San Salvador, 4 October 2012.

¹⁸⁶ Interview with Sergio Montealegre, Coordinator of REDCA+, Central American Network of People Living with HIV. San Salvador, 1 October 2012.

into sterilisation by [public] Health professionals because of their HIV status”.¹⁸⁷ However, after revisions of the final draft made by UNDP, the published report read: “7.6% [of HIV positive pregnant women] reported the impression that at some point a [public] Health professional may have coerced them into sterilisation due to their HIV status” (UNDP and Ministry of Health of El Salvador, 2010). What would have been a scandal with severe political implications was watered down considerably.¹⁸⁸

The international donor community providing funding for the HIV response in El Salvador at present still does little to empower organisations of people living with HIV to work on human rights.¹⁸⁹ In the view of civil society interlocutors, international funders still provide their support to the HIV response from a commodity provision perspective, rather than a human rights-based approach. The commodity provision approach privileges the number of people reached, rather than the holistic situation of beneficiaries that takes into account all critical enablers to their well beings, including livelihoods, human rights, social integration, etc. (Schwartzländer et al., 2011). It also fosters organisations working on HIV to abandon their militant role and integrate an industry of health and development professionals occupied in following imperatives of donors and policy makers (Seckinelgin, 2008).

The government: from opponent to champion of rights-based HIV norms

The chronology of the positioning of the successive El Salvadorian governments around international human rights-based HIV norms demonstrates the significant extent to which CBOs of people living with HIV influenced the diffusion of international norms affecting this population. The El Salvador government effected a complete reverse in its positions, from contesting the universal and free provision of ARVs to championing such norm among other governments around the world contributing to the cascade of such provision that ensued, to the point that virtually every state in the world has adopted the principle of universal free access to ARVs (Kavanagh et al., 2015). This U-turn demonstrates that, as Acharya points out, states can redefine their positions in relation to international norms over time even after a norm has been localised or contested, leading to various waves of rapprochement to the original formulation of the international norm (Acharya, 2004).

¹⁸⁷ Draft *Estudio de Estigma y Discriminación en Personas con VIH*, Informe de El Salvador, C.A, 2009.

¹⁸⁸ Interview with Jaime Argueta, Director of the HIV unit, *Procaduría* of Human Rights, San Salvador, 5 October 2012.

¹⁸⁹ Interview with Claudia de Morales, Development Coordinator, UNDP, El Salvador, San Salvador, 9 October 2012.

CBOs' strategies towards state representatives in El Salvador underpin Brown's attention to national leadership in the way norms are diffused (Brown, 2014), adding the important variable of hierarchy, not only among state representatives, but also among norms depending on the governance system where these norms sit. The CBOs studied in El Salvador chose to try to influence norms within the human rights system leveraging such influence to affect other norms within HIV governance in order to gain access to ARVs. By framing such demand as the right to health, they activated actors in the human rights system, which benefits from robust compliance mechanisms (such as the IACHR) and the involvement of state representatives at the highest level of hierarchy. In contrast with CBOs in Ukraine and Uganda, which made some inroads among health authorities but not among other state representatives, CBOs in El Salvador managed to influence the President and the ministers of foreign affairs and justice, highest in the government's hierarchy.

From the point of view of state representatives themselves, this complete reversal of positions regarding the provision of ARVs confirms at least three key conditions outlined by Cortell and Davis regarding the domestic salience of international norms which CBOs in El Salvador have helped build (Cortell and Davis, 2000). The government eventually perceived that the adoption of the norm supported its own interests; state representatives changed their political rhetoric contributing to generating collective understanding of the new norm to the point of making free provision of ARV a core government policy; and the government took advantage externally to become a champion socialising force persuading other governments to follow the same policy.

The political journey of the successive conservative Arena governments, in power between 1989 (not long after the diagnosis of the first case of AIDS in 1984) and 2010, in relation to the HIV response is complex and its legacy still looms over the current political response to HIV in El Salvador. When in 1999 Miranda filed his case against the ISSS before the Supreme Court, state representatives both within the human rights and health sectors questioned the legitimacy of a small group to represent the larger population of people living with HIV. In 2000, the Ministry of Health declared that it was impossible to provide treatment for people living with HIV in El Salvador because it would lead the ISSS to bankruptcy in less than two years.¹⁹⁰ However, at the time, there was already a precedent in Central America. In Costa Rica, the Supreme Court had ordered in 1997 that the National Health Service provide

¹⁹⁰ Interview with Herbert Betancour, UNAIDS Country Coordinator and former Minister of Health, San Salvador, 9 October 2012.

ARVs to patients on the grounds that economic interest cannot be prioritised over the right to health (Castillo, 2011). For some government representatives, it began to be clear that the financial argument was going to be difficult to sustain given the Costa Rican precedent.¹⁹¹

With the petition being taken to the IACHR, the case took a completely different dimension. This time, it was El Salvadoran government being taken to court, not just the ISSS and this exposure was taking place before a regional human rights body, highly regarded in the international human rights architecture. Still, in 2000, the Government sent a panel of experts to the IACHR to argue against the provision of ARVs on the grounds that the ISSS did not have the necessary technology to provide this kind of treatment to people living with HIV.¹⁹² The panel failed to convince the IACHR Commissioners. Soon after the Commission dictated Precautionary Measures demanding that the Government provide ARVs to all the petitioners, it communicated to the Commission that by November 2000 it would initiate a dialogue process with the plaintiffs aimed to reach a settlement. The beginning of the dialogue process signalled the beginning of a change in the government's position, and the tacit admission that it needed a negotiated way out to their situation.¹⁹³

Until the filing of Miranda's petition, the provision of health care had not been seen from the human rights angle. Among public health care providers and even health authorities, there was widespread ignorance of the right of patients to health, an ignorance which continues to date.¹⁹⁴ The extent to which the IACHR embraced this issue as a broader human rights deficit no doubt made the government react. It also marked the ability of the group of people living with HIV to intertwine norm diffusion processes from the human rights system and HIV/AIDS governance. The Director of the ISSS at the time, Vilma Escobar, understood the damage caused to the government's image abroad and decreed the provision of ARVs by the ISSS, making it available to all people living with HIV eligible to access the ISSS services. In 2004, the Head of the National HIV programme extended the free provision of ARVs to the rest

¹⁹¹ Interview with Herbert Betancour, UNAIDS Country Coordinator and former Minister of Health, San Salvador, 9 October 2012.

¹⁹² Interview with Dr Rodrigo Simán, former Head of the HIV Programme, Ministry of Health. San Salvador, 1 October 2012.

¹⁹³ Interview with Claudia de Morales, Development Coordinator, UNDP, El Salvador, San Salvador, 9 October 2012.

¹⁹⁴ Interview with Ana Nieto, Head of the *Programa Nacional de ITS/VIH-SIDA Ministerio de Salud Pública y Asistencia Social* (National HIV Programme), San Salvador, 1 October 2012.

of the public health service.¹⁹⁵ By 2004, President Francisco Flores had already made HIV a matter of national priority.¹⁹⁶

The combination of strategies towards external actors and among internal actors was critical in influencing the state. The government's embarrassment of being exposed before the international community by its own citizens through a highly publicised case before the IACHR was intense. For years, there was no international forum involving the El Salvadoran government where Miranda's case was not mentioned. It was particularly damning at the Organisation of American States, where El Salvador was trying to re-position itself as a "democratic state that respects human rights."¹⁹⁷ Internally, the sustained pressure on the government by Atlacatl with the above-mentioned unprecedented street and media mobilisation pushed the engagement with the government to a level of regular interaction. This engagement was nourished by constant media support for Atlacatl, and became one of the key tools the organisation used to counter the government opposition to providing ARVs to people living with HIV.¹⁹⁸

A key political goal for the government throughout most of 2000s was to reach an agreement with the plaintiffs and avoid a final decision by the IACHR. Negotiations lasted over five years, until the Friendly Settlement was signed in 2007. The ISSS finally admitted publicly to shortcomings in its HIV/AIDS policies, and the media hailed the agreement as reconciliation between civil society and the state. Government representatives considered that concessions in the 2007 Friendly Settlement were minimal considering the length of negotiations, which they attributed to Atlacatl's delaying tactics to obtain the maximum advantage of the process.¹⁹⁹ At the end of the long process, El Salvador had completed its U-turn in their contestation of a critical human rights-based HIV norm, from denying the sustainability of the provision of ARVs to a very small portion of people living with HIV, to championing universal access to HIV. In this process, El Salvador had become a regional leader in the HIV response (Merino, 2012).

¹⁹⁵ Interview with Dr Rodrigo Simán, former Head of the HIV Programme, Ministry of Health. San Salvador, 1 October 2012.

¹⁹⁶ Interview with Herbert Betancour, UNAIDS Country Coordinator and former Minister of Health, San Salvador, 9 October 2012.

¹⁹⁷ Interview with Dr Rodrigo Simán, former Head of the HIV Programme, Ministry of Health. San Salvador, 1 October 2012.

¹⁹⁸ Interview with Odir Miranda, Director of Atlacatl, San Salvador, 4 October 2012.

¹⁹⁹ Interview with Dr Rodrigo Simán, former Head of the HIV Programme, Ministry of Health. San Salvador, 1 October 2012.

By presenting their case to the IACHR, the CBOs analysed in El Salvador influenced an external actor in the regional human rights system with the power to influence the government's positions not only around human rights, but also within national HIV/AIDS governance. An inverse leveraging was attempted by CBOs in Ukraine and Uganda as these CBOs tried to influence human rights norms using their influence over the HIV response. Unlike in Uganda and Ukraine, CBOs in El Salvador gained influence within the human rights system, which has stronger regional norm compliance systems (Keck and Sikkink, 1998; Hertel, 2006) such as the IACHR and the involvement of representatives at the top of the hierarchy of the state, which they leveraged to influence HIV/AIDS governance in their country.

The coming to power of the Faraundo Martí National Liberation Front (*Frente Faraundo Martí de Liberación Nacional*, FMLN) in 2009 after decades of successive Arena governments made a significant impact on the political scene but did not change dramatically the positions of El Salvador as a resolute proponent of human rights-based HIV norms. The FMLN, once a Marxist guerrilla movement, had transformed into a left-wing political party. The FMNL focused on the rights of the most marginalised sectors of society. The new government attracted a great degree of sympathy among the LGBTI community and from other populations at higher risk of HIV. The HIV response presented itself as a natural fit for the new government's social policies.²⁰⁰ However, at the end of the negotiation process the HIV response had become one of the strongest selling points of the previous conservative governments. This positioning had also contributed to further fragment civil society organisations working on HIV most of which, overtly or discreetly align themselves to one political party or the other in a highly politicised society (Burnel and Gerrits, 2010). With the FMLN in power, government priorities on HIV shifted from a focus on treatment of people living with HIV to a stated focus on prevention among key affected populations and promotion of human rights of these populations, especially the LGBTI community, much in line with the latest priorities of international donors, including the Global Fund.²⁰¹

²⁰⁰ Interview with Sergio Montealegre, Coordinator of REDCA+, Central American Network of People Living with HIV. San Salvador, 1 October 2012.

²⁰¹ Interview with Ana Nieto, Head of the *Programa Nacional de ITS/VIH-SIDA* Ministerio de Salud Pública y Asistencia Social (National HIV Programme), 1 October 2012.

Conclusion

The CBOs of people living with HIV studied in El Salvador, particularly Atlacatl, influenced the diffusion of international norms in EL Salvador to the point of making the government change its position on the delivery of ARVs from frontal opposition to championing universal and free provision worldwide. Unlike in the cases of CBOs in Ukraine and Uganda, CBOs in El Salvador managed to rally both key external actors (in particular the IACHR) and key internal non-state actors (such as the medical trade union and the media) to claim for the right to ARV treatment for people living with. The critical differentiating factor between the strategies of El Salvadorian CBOs to influence norm diffusion as opposed to those in the other case studies is that organisations of people living with HIV in El Salvador sought to reach a large proportion of El Salvadorian society. The national media campaign initiated by the Atlacatl led to significant public support, including social leaders. When the IACHR decided in favour of the CBO representatives, the state was considerably isolated internally and externally in its contestation of the provision of ARVs. The result was a total reverse in its position to the extent that El Salvador became one of the most decisive proponents of universal access to ARV regionally.

CBOs in El Salvador worked simultaneously on norm diffusion processes under both the human rights system and HIV/AIDS governance, advocating to government representatives relevant to both governance systems, intertwining them both and eventually obtaining broad consensus in government which Ugandan and Ukrainian CBOs were unable to achieve. Crucially, CBOs in El Salvador leveraged their influence among higher state hierarchies involved in the human rights system by framing the provision of ARVs for people living with HIV, apparently a health issue, as a realisation of the rights to health, an international human right norm, to influence the government to adopt the universal and free provision of ARVs as a human rights-based HIV norm within HIV/AIDS governance.

Rather than extreme context of marginalisation, violence and criminalisation described in the previous case studies, it was the dire prospect of dying of AIDS which united people living with HIV. This led to the almost desperate direct embracing of the right to health as an absolute principle that did not require translation or vernacularisation to conform the local text into local beliefs as the resonance dilemma would suggest. Nor did these CBOs have choice as regards to the advocacy dilemma of vernacularisation (Levitt and Merry, 2009). Much as obtaining free and universal access to ARV was unthinkable in a poor country ravaged by

decades of civil war, it was a matter of life and death that required breaking any pre-existing strategy or status-quo.

The El Salvador case study contributes to the study of hierarchies among governance systems when norms from several of these systems compete over a normative issue which the Ukraine case study describes as well. This chapter shows how in the context of El Salvador human rights norms mattered a great deal more to the government than norms of global HIV/AIDS governance and demonstrated that having agency in the international (or regional) human rights system guaranteed more influence in the diffusion of norms than agency just in HIV/AIDS governance. By bringing a health-related case as a human rights case to the national and regional judicial structures, CBOs in El Salvador effectively linked together two separate governance systems each with their own international norms: HIV and human rights. This made it possible to ensure that all relevant government representatives, those dealing with the HIV response on one side, and those dealing with human rights and foreign policies on the other, were contemporarily concerned by the judicial outcome of the case and its impact on the internal and external image of the government.

8. CONCLUSION

Conclusion overview: the influence of CBOs on domestic practice

A considerable part of the empirical analysis provided by the field case studies in this thesis contributes to respond to the central research question: what role can CBOs of people at higher risk of HIV play in the diffusion of human rights-based HIV norms domestically? With various degrees of influence, the findings of each of the case studies demonstrate the ways in which the CBOs of people at higher risk of HIV studied play a role in the domestic appropriation and implementation of international human rights-based HIV norms. These findings merit further research and exploration for norm diffusion literature as to the role CBOs of people at higher risk of HIV can play in the diffusion of international norms and for wider IR literature about the influence CBOs may have on the domestic practice of such norms.

The case studies have found various ways in which the CBOs studied have influenced norm diffusion, either or both generating their own local practice based on their embracing of human rights-based HIV norms; and influencing positions of some key external and/or internal actors in the diffusion of international HIV and human rights. As a first finding, all of the CBOs studied build-up representation and legitimacy through the assimilation of international norms. The organisations of transgender people analysed in Honduras struggle to gain influence due to the weakness of their organisational structures and lack of resources, while the LGBTI organisations analysed in Uganda for example have stronger organisational and financial resources which allow them to sustain their action both domestically and among external actors. However, in all cases studied, the assimilation of international human rights and HIV norms is pivotal in the cohesion and objectives of these CBOs and in the identification of members with these organisations.

The CBOs studied provide services and interventions based on the international norms owned by the organisations. All CBOs analysed base their interventions in support of the communities they serve on international human rights, HIV or both sets of norms. This constitutes local practice and is noted among the organisations of drug users in Ukraine, people living with HIV in El Salvador, LGBTI people in Uganda and transgender women in Honduras analysed through the case studies. In Ukraine, the organisations of drug users analysed implement harm reduction programmes based on international human rights-based HIV norms with the support of international donors and NGOs and are recognised by the

Ministry of Health as contributing to the national response to HIV among drug users. A contribution these organisations make by bypassing the rejection of such norms by key state actors such as the Ministry of Interior, which has created a context of persecution against drug users. The CBOs studied in both Honduras and Ukraine have also generated local practice for the implementation of international human rights-based HIV norms through their interventions, even when their respective governments fail to effectively integrate such norms into their national policies.

Some of the CBOs in this thesis generate alliances among external actors in one or more norm diffusion process, especially among donors and HIV governance bodies (as in Ukraine) in the case of HIV norms and treaty enforcement mechanisms (for example the IAHRC in the case of El Salvador) and international NGOs (Uganda) in the case of human rights norms. The LGBTI organisations studied in Uganda have influenced external actors such as other governments, UN agencies and international NGOs to halt attempts in Parliament to introduce legislation contrary to international human rights norms protecting LGBTI people. Some of the CBOs studied also try to influence internal non state actors, such as social movements and the media in the case of El Salvador, and sympathetic representatives of the state (either in the executive, the legislative or judicial branches) as in the case of El Salvador and Uganda. The case of El Salvador describes how, in order to appeal to mainstream media, the CBOs of people living with HIV chose to focus on demands around the HIV status of their members rather than championing rights associated with the sexual orientation of most of these members. Evidence of the influence of CBOs in the diffusion of international norms is however most compelling in this last case study of organisations of people living with HIV in El Salvador, who were able to influence national practice to the extent that the government completely reversed its rejection of universal and free access to ARV treatment for people living with HIV and became an international champion of such norm.

Finally, the El Salvador, Ukraine and Uganda cases describe how the CBOs studied interact simultaneously with various norm diffusion processes. Atlacatl and other CBOs in El Salvador managed to influence two of such processes at the same time, intertwining them thus affecting their respective outcomes. These CBOs leveraged their influence among actors within the international human rights system of governance to obtain the free provision of ARVs within the within HIV/AIDS governance.

Contributions to IR literature

This demonstrated role of the CBOs analysed in the empirical chapters in the domestic diffusion of international norms call for further analysis in each of the three main areas of study in IR referred to in this thesis: norm diffusion, global health, and vernacularisation. Firstly, the findings in the thesis make a case for the need to further research and explore the role that CBOs of people at higher risk of HIV can play when analysing how international HIV norms are integrated into national practice, a stated central objective of any norm diffusion theory (Cortell and Davis, 2000; Krook and True, 2010). This role challenges the lack of attention given to CBOs in norm diffusion literature, often focused on states as norm takers and on proponents or opponents to particular norms at the global level (Krook and True, 2010; Stoeva, 2010), and questions the validity of any analysis of norm diffusion processes that does not take into account the role of local community organisations.

This thesis refers extensively to global health literature, which has contributed to bridging this gap of attention on non-state actors in the area on which this thesis focuses: the response to HIV. Global health literature considers that although the HIV response is largely regulated by international norms (Elbe, 2009; Nguyen, 2010; Seckinelgin, 2012), CBOs of people affected by the disease are essential elements of community mobilisation for health as they reach the populations who are most marginalised and therefore most difficult to reach through the public health system (Campbell and Cornish, 2010; Gutierrez et al., 2010; Rodríguez-García et al., 2011; de Zoysa, 2012; Mburu et al., 2012). However, global health authors tend to see the role of CBOs solely as complementing public health systems through the implementation of public health interventions at the local level among the populations these organisations serve, thus contributing to the national health response. This thesis found that the CBOs studied generate their own practice when health authorities fail to reach the populations they represent. At times, as in the case of Ukraine and Uganda, the CBOs studied had to bypass their own governments to provide their HIV responses due to persecutory policies against drug users and LGBTI people respectively. All case studies show that this local practice in response to HIV is closely based on international human rights-based HIV norms, rooted in the principle of non-discrimination in the provision of health, which these organisations and their members have embraced.

Finally, the thesis has also largely relied on vernacularisation theory to help explain the role that the CBOs of people at higher risk of HIV studied play in the assimilation of

international norms among their members. The case studies however show that, in most of the CBOs of people at higher risk of HIV analysed, the assimilation of international norms is indeed more straightforward and takes far less adaptation to the local context than vernacularisation authors suggest. This challenges the resonance dilemma in vernacularisation, which claims that to have an impact, human rights ideas must be adopted locally so that they resonate with existing local ideologies (Levitt and Merry, 2009). All the populations represented by CBOs of people at higher risk of HIV analysed in the case studies are highly discriminated against and pushed out of local social structures. Therefore, CBOs tend to appropriate precisely those international norms which most challenge local ideologies. For example, LGBTI organisations in Uganda embrace international norms protecting people based on sexual orientation and gender identity which pose a major challenge to local religious and social beliefs shared by many of their members.

The case studies also question the advocacy dilemma in vernacularisation as regards to CBOs and HIV. This dilemma states that, when organisations align their advocacy on human rights with existing issues and strategies, they are “more readily accepted but represent less of a challenge of status quo” (Levitt and Merry, 2009: 458). The mobilisation of CBOs of people living with HIV in El Salvador demanding free access to ARVs shows that is not necessarily the case. The considerable cost of ARV treatment for a low income country and the lack of precedent among similar countries made this demand a major challenge to the status quo. Yet, this demand was eventually met by the government when it had become damaging for the government’s domestic and international reputation not to provide free ARV treatment.

Further contributions to norm diffusion theory

The thesis offers three main points of further reflection for norm diffusion theory specifically. Firstly, on the importance of the later stages of norm implementation. The influence of CBOs of people living with HIV in El Salvador on the government’s U-turn from its previous contestation of the provision of universal and free ARV treatment for people living with HIV demonstrates that states can indeed overturn their positions in relation to international norms even after they have localised or contested them (Acharya, 2004). This highlights the fact that changes in state positions can take place towards the later part of the norm diffusion process through the action of local actors, such as CBOs, and not just at the earlier stage of norm socialisation, when external actors interact with states, which is the focus of much of norm diffusion literature (Keck and Sikkink, 1998; Finnemore and Sikkink, 1998, Stoeva, 2010).

Secondly, the description of external actors, primarily outsider proponents, and state representatives through the case studies shows contradictions in the positions regarding international norms of both sets of actors. This is mostly due to the fact that both states and external actors (such as donors and other states) may behave differently in relation to various international norm diffusion processes from different governance systems converging in one country. The Ukraine case study shows how the state commits to adopting harm reduction norms as part of its HIV/AIDS governance, but at the same time it persecutes drug users. In Uganda, the US and the EU fund a large part of the HIV response, which discriminates against the LGBTI population whose rights these two actors are strongly advocating to be respected by the Ugandan authorities.

These contradictory positions underpin the fact that both the state and external actors are often represented by different institutions in each norm diffusion process depending on which governance system that process belongs to. In Ukraine, the state is represented by the Ministry of Health when it comes to HIV and harm reduction policies, and by the Ministry of Interior regarding security and drug policy. In the case of the bilateral relations between the United States and Uganda, the Department of State deals with human rights whereas PEPFAR supports the HIV response. This contrasts with the wide consideration in norm diffusion literature of states and external actors (in particular outsider proponents or entrepreneurs) as single structures with unambiguous and stated, although changeable positions through the norm diffusion process (Nadelmann, 1990; Cortell and Davis, 2000; Stoeva, 2010; Keck and Sikkink, 1998; Hertel, 2006).

Thirdly, the intertwining of norm diffusion processes from various governance systems described in the case studies as being a key strategy undertaken by the CBOs analysed offers important reflections as to the role of hierarchies in the study of norm diffusion. Norms compete with other norms over particular normative points (Meyer et al., 1997; Finnemore and Sikkink, 1998). The thesis shows that such competition takes place also between international norms belonging to different governance systems. In Ukraine, for example, norms from international drug policy compete with harm reduction norms from international HIV/AIDS governance. The former persecute drug users, the latter upholds their human rights treating them as patients. A norm would prove its higher hierarchical status by being the one that is actually implemented (complied with and enforced) by state actors more consistently.

The widespread persecution of drug users and organisations providing services to this

population in Ukraine illustrates well how these hierarchies manifest themselves. The case study describes a norm *disappropriation* of harm reduction norms. Although harm reduction norms (treating drug users as patients) have been appropriated by the state (represented by the Ministry of Health), such norms are in practice overturned (*disappropriated*) by an opposing international norm (persecuting drug users) also appropriated by the state (through the Ministry of Interior). This phenomenon is a variation of Acharya's description of norm displacement when an international norm fails to overturn a local norm (Acharya, 2004), and again highlights the importance of better understanding and considering the phase of norm implementation in norm diffusion theory.

International norms hierarchies mirror hierarchies within the state itself given that the state is represented by different actors in different norm diffusion processes. The same applies to external actors. Such hierarchies define the hierarchy of the governance system where the process sits. For example, in El Salvador, the regional human rights system is higher up in hierarchy than HIV/AIDS governance. State representatives at the higher level are involved in the former, underpinning the critical role of national leadership in the effective appropriation of international norms (Snow et al., 1986; Tarrow, 2005; Brown, 2014); and external actors in the regional human rights system, like the IACHR, have a legally binding power which organs of the HIV/AIDS governance do not have. The human rights system proved to be a higher hierarchical level than HIV/AIDS governance when the government eventually decided to provide ARV treatment to people living with HIV.

Understanding CBOs' influence in the diffusion of norms

Building up representation and legitimacy through norm appropriation

The case studies showcase the importance that the appropriation of international norms from both the HIV and the human rights governance systems has in the development of the CBOs of people at higher risk of HIV analysed. This assimilation is also critical among the CBO members interviewed in terms of empowerment and self-esteem and identification of these individuals with their organisations and it plays a significant role in the building up of the legitimacy of these CBOs as representatives of the population they claim to serve, as well as their organisational strengthening and sense of purpose. This finding offers a new direction of analysis in norm diffusion literature, which mostly focuses on the appropriation or contestation of norms by states and not by other internal actors (Risse and Sikkink, 1999; Cortell and Davis,

2000; Björkdahl, 2005; Krook and True, 2010).

Testimonies from all case studies describe how both HIV and human rights norms serve to increase the identification of CBO members with their organisations. However, in the case of human rights norms, ownership is also associated with social empowerment, with the perception that these norms can serve as a tool to counter a context of social and state-sponsored violence. This is consistent with testimonies by transgender sex workers in Honduras or drug users in Ukraine referring to themselves as activists or human rights defenders. This is not always the case with HIV norms, which in many cases, for instance among the transgender sex workers interviewed in Honduras, and undoubtedly among people living with HIV in El Salvador, are often the point of entry for CBOs to attract new members but then gradually become less important for members as these norms play less of a role in the empowerment of members and the cohesion of the organisations compared to than human rights norms.

This assimilation of international norms is in line with vernacularisation theories. The case studies demonstrate that the CBOs analysed play an important role in translating international norms so that they can be owned by the populations they represent (Merry, 2006). However, the case studies indicate that in the particular case of CBOs of people at higher risk of HIV, a key strategy that these organisations undertake is indeed to embrace international human rights ideas, principles and norms with a very low degree of adaptation to local beliefs. The case studies find a common characteristic among all CBOs studied: wide social discrimination and exclusion (including legal discrimination in the case of Ukraine and Uganda and human rights violations committed by the State in all case studies). The shared experience of such exclusion acts as a glue for most CBO members interviewed to identify with each other and with the organisations representing them. This also explains that, for these CBOs, international norms originally formulated are powerful tools precisely because they challenge local beliefs upfront. This is consistent with constructivist ideas as to international norms eventually prevailing over local beliefs (Wendt, 1999; Joachim, 2003) and questions, at least as far as the CBOs of people at higher risk of HIV studied are concerned, the resonance dilemma in vernacularisation theory whereby CBOs need to translate global norms and principles to the local context in order to gain traction among potential supporters (Levitt and Merry, 2009).

As far as HIV/AIDS governance is concerned, there is little doubt that the HIV epidemic and its response has created specific populations that did not exist before, for example, people living with HIV or MSM (Altman, 2005; Tamale, 2011). Both in literature and in HIV/AIDS

governance, these populations are often referred to as communities with intrinsic shared identities as well as social practices (Cohen, 1995; Howarth, 2001; Grow and Allan, 1994). The case studies show how inaccurate and distorted this definition may be as they describe how some of the CBOs analysed adapt to and embrace identity constructs created by external actors as a strategy in order to gain their support. In Honduras, the transgender sex workers interviewed are torn about their identities and the communities they belong to, with very few individuals mentioning LGBTI as their community, let alone MSM. In El Salvador, the people living with HIV interviewed very rarely define themselves as a community. In Uganda, lesbians were outspoken about choosing to portray themselves as belonging to a LGBTI community in order to gain agency and access financial and technical assistance. However, it is evident that HIV creates new vulnerabilities to human rights violations and, even without creating new identities, HIV contributes to the strengthening of organisations representing populations at higher risk of HIV, helping their member identify with each other around a common objective of promoting human rights norms for the protection of their population. HIV plays this role in all CBOs studied, even when, with the exception of CBOs people living with HIV in El Salvador, responding to HIV itself is not necessarily the main objective of these organisations.

Providing services and interventions based on international norms

All CBOs studied in this thesis provide services to their members. Considering that the organisations chosen for the empirical chapters represented populations at higher risk of HIV in countries particularly hostile to these populations, either in terms of persecution, criminalisation or social stigma and discrimination, the vast majority of these services were based on international human rights principles and norms. These CBOs diffuse such norms among their members either in response to the human rights context these populations endure, to provide HIV related services for them, or both.

The findings of the thesis therefore respond affirmatively to the question whether there can be local practice implementing international norms carried out by non-state actors, even when this practice is not aligned to the policies of state actors. The local practice of HIV responses based on international human rights norms that the CBOs of people at higher risk of HIV analysed generate through their interventions, at least in contexts of persecution of the population these CBOs represent, reaffirms the need for norm diffusion literature to consider non-state actors as generators of practice around international norms and not to focus only on

the national practice generated by states (Risse and Sikkink, 1999; Acharya, 2004; Krook and True, 2010).

The transgender organisations studied in Honduras provide peer-to peer HIV prevention services among sex workers and human rights interventions, including psychosocial support to victims of violence and accompaniment to present complaints to the police or the judiciary. As the case study describes, these interventions are not directly supported by government-led programmes, they are mostly initiatives by transgender organisations to respond to widespread transphobia, including the impunity associated with it, and high risk of HIV among transgender people. The testimonies in the case study show the central role that the embracing and owning of human rights norms by members play in these organisations providing such services and in individuals seeking them.

Similarly, both the case of LGBTI organisations in Uganda and drug users in Ukraine describe moments in the development of both sets of organisations when they have had to bypass state policies which either persecuted their populations or denied essential HIV services to their members. Until well into the 2010s, LGBTI organisations provided HIV services to MSM and transgender women in clinics which were considered illegal by the Ugandan authorities and often raided and shut down by the police. These services contributed to the domestic response to HIV, but not to the government-led national response. The National Strategic Plan against AIDS disregarded the LGBTI population in its analysis of the epidemic and did not contemplate any interventions to address the epidemic among this population and until recently, international donors did not fund HIV interventions for MSM and transgender people in the country.

The case study on Ukraine describes how the CBOs of drug users analysed need to bypass government policies repressing drug users in order to provide harm reduction programmes for this population. The chapter shows that although these services are recognised by the Ministry of Health and financed by international donors, both practitioners and clients are subject to severe persecution from law enforcement officers, including through arbitrary detention, harassment, disclosure of confidential clinical data, and other human rights violations. In this particular case, although the participation of CBOs is included in the national response to HIV among drug users, this is largely due to the CBOs' own initiative, not as implementers of a state-led response. The existence of harm reduction programmes is entirely dependent on the local practice generated by these CBOs with international funding,

without which there would be no service providers for these programmes in the country as there is no national budget and no internal political support to sustain them.

Playing a recognised role as contributors to the national HIV response

As indicated in the previous paragraphs, Honduras, Ukraine and Uganda case studies show the significant role that the CBOs analysed play in contributing to domestic responses to HIV through the provision of HIV services, especially among peers, which no other organisations are able to provide. This contribution by CBOs has been acknowledged (Reza-Paul et al., 2008; de Zoysa, 2012; Cornish et al., 2012) but also minimised in HIV-related literature (Beckman and Bujra, 2010; Boesten, 2011; Marsland, 2012).

All case studies however, describe how CBOs have eventually also been recognised as contributing to the national HIV response. In the cases of Uganda and Ukraine, the respective ministries of health have included such responses in their national plans even when in both cases it is international donors which are financing the work of CBOs and other parts of government and other state structures have created a hostile environment for these organisations to operate. The work of transgender organisations in the provision of HIV services in Honduras has never been contested by the authorities, although these organisations work with very limited financial or technical support from either national or international actors. In El Salvador, CBOs of people living with HIV are at the core of national policies on HIV, with direct financial support from health authorities. In all the cases studied, except in Honduras, the recognition of their contribution to the national response has allowed CBOs to open a line of dialogue with key players in the diffusion of international HIV norms in their countries, namely the health authorities in Ukraine and Uganda, and also political figures at a higher level in the case of El Salvador. In all cases, the CBOs studied have received funding from international HIV donors which has facilitated a dialogue with these external actors in order to seek their support to influence the government.

Although this key role in the implementation of the national response to HIV has generally contributed to the CBOs analysed accessing resources to strengthen their often precarious organisational structures, it alone cannot explain the significant level of agency CBOs require to be able to influence not just HIV, but also human rights and other related governance systems. In the case of transgender organisations in Honduras, despite being the only ones reaching the population with the highest HIV prevalence in the country, these organisations enjoy very limited access to HIV funding. A similar situation occurs among LGBTI

organisations providing HIV services to MSM in Uganda. In both cases, these very organisations are also the only ones on the ground providing human rights-based services to the populations they represent.

This fact exposes a reality in both human rights and HIV policy and literature. The focus on the individual in both human rights and public health approaches to HIV means that both underestimate the crucial role CBOs play in the provision of human rights-based responses to HIV. Some authors have highlighted the fact that the HIV response is highly biomedicalised, and therefore tends to individualise the relationship between norms and affected populations, again relegating the role of CBOs to passive actors with largely tokenistic roles in HIV/AIDS governance (Mann, 1988, Seckinelgin, 2005; Nguyen, 2010; Marsland, 2012). The case studies show how this biomedicalisation of the response takes prominence even among outsider proponents of HIV norms, such as donors and organs of the HIV/AIDS governance like the WHO, which otherwise state in their policies the importance of attending to all structural factors that can undermine the HIV response.

The CBOs of populations at higher risk of HIV studied in the thesis are confronted with HIV programmes which often take these organisations into account in the delivering of biomedical interventions, such as condom distribution or voluntary testing and counselling, but which do not attend to the wider needs of beneficiaries; for instance, the need to respond to violence against CBO members in the case of transgender organisations in Honduras. However, the CBOs analysed offer responses to HIV which are deeply rooted in international human rights principles, appropriating international norms in a way that has the potential to offsetting to a considerable extent the prominence of biomedicalisation in the HIV response. The El Salvador, Ukraine and Uganda case studies describe contexts where the CBOs analysed have been able to move away from the imperative of therapeutic sovereignty (Nguyen, 2010), or the treatment regime (de Wall, 2006), as they are seen as key in the implementation of the HIV response looking at the wider needs of individuals beyond treatment and with an agenda to advocate for change.

Influencing external and internal actors

The case studies show that the CBOs analysed try to influence both key internal and external actors within global HIV/AIDS governance and the international human rights system. The case of transgender organisations in Honduras shows that the assimilation of international norms within the community has not translated into influencing key external and internal actors.

However, the CBOs studied in Uganda and Ukraine have been able to mobilise external actors, donors and, in the case of Uganda, also a number of international LGBTI and human rights organisations, governments and even UN organs, whereas Ukrainian CBOs have been able to exert some influence on both internal (Ministry of Health) and external (donors) actors in HIV/AIDS governance. CBOs in El Salvador were also able to influence both internal non-state actors (media, medical trade union) and outsider proponents (the IAHRC).

All the case studies in this thesis describe the changing role of external and internal actors in the appropriation or contestation of norms in each of the countries studied. This is consistent with the dynamism of the diffusion of international norms defended by a number of authors (Krook and True, 2010; Brown, 2013; Acharya, 2004). CBOs themselves are internal proponents of norms and the analysis of these organisations undertaken in this thesis contributes to the opinion by some authors that social movements have facilitated a boomerang effect of contestation of the appropriation or localisation of a particular norm by the state with the potential to alter it (McCarthy, 1997; Keck and Sikkink, 1998; Hertel, 2006). These authors however, centre their analysis on international social movements (thus, outsider proponents) whereas the thesis provides evidence that some CBOs with precarious organisational structures, can effectively unleash such a boomerang effect by influencing both outsider proponents and other internal state and non-state actors.

The case studies describe some of the key strategies that the CBOs analysed lay down to try to influence key external actors which merits further research and exploration as to how critical these strategies might be in influencing the outcomes of norm diffusion processes. Without appealing to the IACHR, the El Salvadorian CBOs of people living with HIV might have never been able to influence the government to overturn its contestation of the provision of free ARVs. Without reaching out to international NGOs, key governments and other outsider proponents of human rights norms, LGBTI organisations in Uganda would have not been able to minimise the impact of anti-homosexuality legislation. Without international HIV organisations championing harm reduction responses to HIV, CBOs of drug users in Ukraine would have never existed beyond small peer support and drug rehabilitation groups.

However, the strategies to build agency by the CBOs studied have had to conform to some of the objectives and requirements of key external and internal actors, although the degree of flexibility in compromising their own principles or objectives varies from organisation to organisation. As mentioned earlier, at the most basic level of compromise CBOs often adopt

definitions of communities artificially constructed by external actors. For instance, the notions of LGBTI community or community of MSM, which were adopted widely among donors, international NGOs, and in human rights and HIV literature. In some CBOs, such compromise can go as far as to occasionally accept biomedical arguments of the HIV response as a means to obtain support to human rights-based approaches to HIV. This is illustrated by the ability of Ugandan LGBTI organisations to obtain funding from HIV donors and establish a dialogue with the state representatives most concerned with the epidemic such as the Ministry of Health on framing their arguments advocating for the need to protect the rights of the LGBTI community as a means to curb the epidemic, instead of an end in itself. Atlacatl in El Salvador took the strategic decision to renounce advocating for the rights of LGBTI people and to focus exclusively on the right to health for people living with HIV in order to obtain wider support from the mainstream media, social movements such as the medical doctor's union, and the general public.

Intertwining norm processes, understanding competition and hierarchy

Most of the CBOs analysed in the case studies try to influence key norm diffusion processes that affect them simultaneously. In the case of El Salvador, CBOs of people living with HIV influenced the diffusion of both human rights and HIV norms through the petition at the IACHR bringing a change to the human rights policies of the government regarding people living with HIV as well as to the HIV/AIDS governance of the country, with changes in public health policies about ARV provision and participation of people living with HIV in the elaboration and implementation of public health policies. As a result, CBOs were able to integrate human rights-based HIV norms into national HIV/AIDS governance. This case contrasts with the case of people who use drugs in Ukraine, who influenced HIV/AIDS governance policies in their country around harm reduction, but were unable to shift national drug policy from a highly securitised one to a more human rights-based one. As a result, Ukrainian drug users' limited gains in public health are constantly undermined by contradicting state policies criminalising them and frequent violations of their human rights.

This interaction between processes from different governance systems is largely possible as CBOs strategize according to the state structure they need to influence. For example, CBOs in Ukraine and Honduras tried to influence the Ministry of Health in the case of international HIV norms, but CBOs in Ukraine engaged with the Ministry of Interior regarding international drug policy norms and CBOs in Uganda dealt with MPs to stop the passing of the Anti-

homosexuality Bill. This diversification of strategies towards the state contrasts with norm diffusion literature which often refers to norm takers as a monolithic structure: the state (Checkel, 1998; Acharya, 2004; Domínguez, 2010). The case studies show that within the state there are various norm takers holding different positions in relation to particular norms exposing the inconsistency of states which can commit simultaneously to implementing opposing international norms from various governance systems. For instance, Ukraine has committed to adopting international norms on drug policy criminalising drug users and also human rights-based HIV norms which treat drug users as patients and not as criminals.

Norm diffusion literature does offer deeper analysis on the variety of external actors in norm diffusion processes and pinpoints that these may vary from process to process depending on the international governance system where each process is nested (Clark, 2001; Kravtsov, 2009; Greenhill, 2010). The case studies show how disparate positions by the same external actor can be, for example by holding opposing positions as donors of the global HIV response and therefore as key players in global HIV/AIDS governance on one hand, and as promoters of certain norms within the international human rights system on the other. For instance, for decades, Uganda obtained significant funding for its HIV response from the US and the UK governments (either directly or through multilateral funding agencies like the Global Fund to which they greatly contribute financially), which were highly critical of the Ugandan government for the persecution of LGBTI people, completely excluded from the national response to HIV until recently.

These inconsistencies both within state structures and within external actors highlight the importance of understanding how CBOs deal with hierarchy in norms and within and among key actors in the diffusion of such norms. In this respect, the thesis builds on the work of some norm diffusion authors looking at the complexity of the normative space and the competition among norms (Meyer et al. 1997; Finnemore and Sikkink, 1998; Reus-Smit, 2009). For these authors, this competition takes place at the international level of norm socialisation among states, not so much internally, when various norm diffusion processes clash at the time of norm implementation. That was the object of the analysis of the intertwining of norm diffusion processes in this thesis since in the case of the HIV response human rights-based HIV norms feed from norms and principles within the international human rights system but are part of global HIV/AIDS governance.

Some of the case studies show how norms from other governance systems, such as drug policies, interfere with the diffusion of HIV norms. The clash between harm reduction norms and drug policy norms in the consideration of drug use described in the case study on Ukraine is a good example of this. Ultimately, it is drug policy which prevails in government's policies creating a context of persecution of drug users. This reality reveals that government representatives in drug policy governance (Ministry of Interior) are higher in the power hierarchy than government representatives within the HIV/AIDS governance (Ministry of Health). In this case, a norm *disappropriation* of harm reduction policies takes place when they compete with drug policy norms. Although both have been appropriated by state representatives, only the latter are implemented by the state's law enforcement structures.

The role of CBOs of people at higher risk of HIV in these related processes is essential to understand how and to what degree they intervene to influence HIV norm implementation and influence the relevant state structures. This builds from the work of some norm diffusion authors who have focused on domestic processes and the role of internal actors, although these authors do not consider CBOs among the actors analysed (Koh, 1997; Checkel, 1998; Farrell, 2001; Acharya, 2004). For example, in the case of organisations of drug users in Ukraine, the prominent role that these CBO play in the implementation of harm reduction programmes, which are deeply rooted in human rights principles, has allowed them to effectively implement human rights-based-HIV norms, almost completely bypassing state structures. Although these organisations have not been able to counter the rejection of international human rights norms by the Ukrainian security authorities who champion the criminalisation of drug use and drug users as key drug policy norms.

The case studies describe how the CBOs analysed take into consideration the development of the HIV epidemic and changes in their HIV/AIDS governance context and take advantage of this context to develop and strengthen. These CBOs often change their main stated objectives and strategies from a purely human rights approach of denunciation and advocacy to purely programmatic responses to HIV and vice versa as a way of adapting to changes in government policies, or the international human rights and HIV/AIDS governance regarding the country where they operate. The case of CBOs of LGBTI people in Uganda is a prime example of this adaptation in the intertwining of simultaneous strategies around more than one norm diffusion process. Most of the agency of these CBOs is directly due to their assimilation of human rights norms and their work as human rights activists. As a result, these CBOs have had considerable influence on external champions of human rights norms, including international human

and LGBTI rights organisations and a number of governments. These in turn put considerable pressure on state representatives in Uganda, especially president and parliament, and this is having an effect in at least stalling the contestation of LGBTI rights by state representatives, even when homophobia is mounting in society. However, Ugandan LGBTI CBOs have made few inroads in influencing these state representatives to change their positions regarding LGBTI rights.

On the other hand, although Ugandan LGBTI organisations play some role in the HIV response, they have only occasionally used the HIV/AIDS governance strategically. It is only recently that they have done so from the point of view of human rights-based responses to HIV, coinciding with a new interest by international HIV donors in human rights principles being applied to the Ugandan HIV response. As a consequence, LGBTI organisations now have a direct dialogue with government representatives concerned with the HIV response, particularly the Ministry of Health, and with it, a political opening that the human rights system did not provide to them. This interconnection has been made possible thanks to the eventual, and as seen above, rare alignment of external actors in HIV/AIDS governance on one hand and outsider proponents of human rights norms on the other to champion human rights-based responses to HIV in Uganda.

The hierarchy between international norms is marked by domestic salience (Cortell and Davies, 2000) among the highest ranked representatives of the state. This underpins the critical role of national leadership in the effective appropriation of international norms (Snow et al., 1986; Tarrow, 2005; Brown, 2014). In this regard, the ability of CBOs of people living with HIV in El Salvador in intertwining processes is largely due to the fact that they leveraged their influence among higher state hierarchies involved in the regional human rights system with their petition to the IAHRC aimed to influence national HIV/AIDS governance, which had the involvement of representatives of the state at a lower hierarchical level. Furthermore, external actors in the regional human rights system, such as the IAHRC have more power of enforcement and influence on states than HIV/AIDS governance. The organisations analysed in El Salvador leverage their influence in the human rights system by framing the provision of ARVs for people living with HIV as a human rights issue thus infusing the HIV response in El Salvador with international human rights-based HIV norms that the government had previously contested.

Conclusion: implications and reflections on the end of AIDS

International norms from global health governance and the international human right systems matter to IR as they impact on the lives and the health outcomes of millions of people and communities (Wolff, 2012; Brown, 2014; Harman, 2012). The diffusion of human rights-based HIV norms into domestic (local and national) practice illustrates such impact and deserves attention in norm diffusion theory as to how such diffusion takes place and which actors are important in the process. The thesis demonstrates that the CBOs of people at higher risk of HIV studied play a role in the diffusion of international human rights-based HIV norms both as implementers of such norms and to ensure their appropriation among the populations they represent. Crucially, some of the CBOs studied can also influence the government and other state representatives at the later stages of norm diffusion, when international HIV and human rights norms are implemented through their integration into national practice, to the point of, in the case of El Salvador, being able to make their government overturn their own positions in relation to a particular international norm. Furthermore, through the simultaneous interaction with norm diffusion processes from global HIV/AIDS governance and the international human rights system, some of the CBOs studied interlink such processes aiming to affect their respective outcomes. These finding merit further research and exploration in IR literature as to the role CBOs play in the diffusion of international norms.

Implications, limitations and future research

Logically, this thesis has several limitations. From the theoretical analysis point of view, the thesis focuses mostly on norm diffusion and related theory within the international human rights governance system and global health (HIV/AIDS governance in particular). The thesis shows important connections between international norms from these governance systems and others, drug policy in particular. However, time and space limitations did not allow a deeper study of other systems which would have provided richer analysis, for example, global security. The same applies to related fields within and outside IR. Vernacularisation theory does have considerable space in the thesis, but social anthropology offers good theoretical frameworks to explore further the nature and factors behind the creation, development and cohesion of CBOs of people at higher risk of HIV. Likewise, although the thesis refers to the local practice generated by CBOs, especially through human right-based HIV interventions, it does not explore debates in IR about what constitutes international practice, which are particularly rich in human rights literature.

The thesis bases its empirical analysis on four case studies. Although they show a wide geographical and epidemiological spread and collectively they represent a variety of populations at higher risk of HIV and a diversity of strength and cohesion of CBOs, the empirical research does not permit to compare a given population in a variety of settings, for example, in contexts where these populations are not as persecuted and criminalised as in the case studies chosen. A case study on women living with HIV in South Sudan which finally did not make it into the thesis due to lack of space would have provided interesting analysis in a situation where CBOs did not seek to influence the diffusion of norms. The findings of the thesis regarding the role of the CBOs analysed in the case studies does not permit to find a set of casual conditions or factors explaining the CBOs' success or failure in influencing national policy, but rather describe ways in which CBOs may influence the diffusion of norms, including key actors in it, highlighting the importance of further exploring such influence in IR literature.

In each case study, the focus of the field research was a small but representative number of CBOs, their leadership and their members. More interviews with other CBOs and more representatives of other social actors and the state would have enriched the analysis, especially in terms of differences in strategies and competition to influence norm diffusion among several CBOs. In this regard, a significant limitation of this thesis is that all case studies focus on CBOs who champion international human rights-based HIV norms for the protection of the populations they represent, without taking into account other organisations or institutions which might be championing opposing international or local norms and trying to influence state structures as well. A study of how strategies of opposing sets of non-state actors relate and clash when trying to influence the diffusion of opposing norms on a given normative issue in a given country would indeed enrich further research on this area.

However, through the findings about the role of CBOs of populations at high risk of HIV in Honduras, Ukraine, Uganda, and El Salvador this thesis demonstrates that without a thorough study of these loose but extremely important structures in the actual implementation of norms among those for which these norms are intended, the study of norm diffusion is incomplete. The thesis shows that CBOs can be crucial in the implementation of norms and presents evidence of CBOs who have been able to alter the outcomes of norm diffusion, both being able to make governments change their minds about their positions in relation to international norms, and also being able to leverage their influence in one norm diffusion process to alter another.

The study of CBOs in this thesis has also brought up critical reflections underpinning the complexity of norm diffusion processes themselves and challenging some widespread preconceptions in norm diffusion literature in general. Firstly, the thesis has extensively analysed norm appropriation, not just among states, but among CBOs representing specific populations. This analysis is essential to understand that through appropriation, CBOs can potentially strengthen their structures and gain agency to attempt to influence norm diffusion processes. This underlines the need to study norm appropriation among external and internal actors and not only among states as norm takers, as is usually the focus of norm diffusion literature.

Secondly, the various strategies of the CBOs analysed regarding various parts of the state show how vital it is to consider the various norm takers in a given country not just as one, the state, as is often the case in norm diffusion literature. The same applies when considering the various roles that a given internal or external actor can play depending on which norm diffusion processes they operate in. This latter point provides an important final contribution of this thesis to norm diffusion literature: the need not to see norm diffusion processes in isolation from each other, and the need to understand hierarchies both among norm takers depending on which governance system hosts the particular norm diffusion process under consideration, and among processes themselves when they contradict each other on a particular normative matter.

Inevitably, each of these reflections and contributions to literature generates new questions for future research. Each of the literature gaps identified in this section lends itself to future research on the role of CBOs at higher risk of HIV. The comparison of such role with other CBOs trying to influence norms in other areas, such as environmental rights for instance, is an obvious and needed area of future research. Further understanding hierarchies within and among norm diffusion governance systems and how related systems interact to each other is imperative.

Final reflections: 'The end of AIDS' and is the AIDS response exception or example?

The empirical analysis of this thesis provides some points of reflection about the way decision makers envisage the global HIV/AIDS response. The thesis describes a tension between investing in the biomedical technologies that can treat and prevent HIV on one hand, and the mobilisation of communities to respond to the epidemic and to the wider needs of their individuals on the other. This should not be a trade-off but, in a context of shrinking financial

resources in global health, it is becoming increasingly an issue for the global response to HIV/AIDS now that for the first time there is enough prevention and treatment technology to see ‘the end of AIDS’, which has become a commonplace expression among actors of the HIV response.²⁰²

UNAIDS’ 20-20-20 targets envisage that “by 2020, 90% of all people living with HIV will know their HIV status. By 2020, 90% of all people with diagnosed HIV infection will receive sustained antiretroviral therapy. By 2020, 90% of all people receiving antiretroviral therapy will have viral suppression” (UNAIDS, 2014:2). It is of great concern that the closer we get to ending AIDS, the more likely it is that marginalised, criminalised and hard to reach populations such as the ones analysed in this thesis will be the 10% left behind at each stage of the 90-90-90 pathway. The combination of a trend towards further biomedicalisation of the HIV response illustrated by targets based on viral suppression on one hand, and the introduction of a growing number of laws further punishing populations at higher risk of HIV on the other, will certainly have great impact on the role, agency and strategies of CBOs representing these populations. This should also be subject of future research.

As the thesis shows, neither the international human rights system nor global HIV/AIDS governance encapsulate in full the essential role that CBOs of populations at higher risk are playing by providing human rights-based responses to HIV. HIV/AIDS governance and its norms often ignore the full array of interventions CBOs carry out which, beyond promoting the human rights of their members, are largely focused on immediate essential needs including physical protection, housing, psychosocial support, or accompaniment. CBOs have a level of legitimacy, reach and commitment to sustaining their support to the populations they represent that no other actor within the HIV/AIDS governance can guarantee. This makes it imperative to fill the evident gap in the consideration of CBOs by IR, global health and human rights-related literature and policies.

The consequences of this oversight on the effectiveness of the global response to the HIV/AIDS pandemic are worth further thorough research. This analysis should be extended to other pressing issues in global health. Policy makers, politicians and academics often talk about the lessons of the unprecedented response to HIV placing part of its impact on the

²⁰² For example, ‘The end of AIDS? Thirty years on, it looks as though the plague can now be beaten, if the world has the will to do so’, *The Economist*, 2 June, 2011.

unprecedented mobilisation of communities, represented by CBOs, and the human rights principles on which the response is based. However, a critical persistent question remains as to whether experience of responding to HIV/AIDS, the connection with human rights, the role of people and organisations affected by the disease are indeed lessons or models for the response to emerging health threats or they represent an exceptional one-off case in the history of global health.

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Appendix 1: Examples of questionnaires for field research interviews

A1.1. Example of interview questionnaire for transgender woman in Honduras

1. How did you know about the (*Colectivo*/other CBO of transgender people)? What services it provides attracted you most to it?
2. What HIV services does this organisation provide? Would you have access to the same services in public health facilities? Why don't you access such facilities instead?
3. How would you summarise this organisation in terms of its objectives and what it represents? Are there other organisations that you know of doing a similar job? Would you go to them for HIV or other services already provided by this organisation? If not, why not?
4. Do you think you belong to a community? If so which community or communities? What makes a community in your opinion?
5. Do you think you belong to the transgender community? And to the LGBT community? If yes, why? what makes you a member of this/these community/ies?
6. Do you feel safer or more vulnerable now that you belong to this organisation? What are your main fears now and how different are they to the ones you had before entering the organisation?
7. What are human rights for you? How do they affect/or not your life? Where have you learned about human rights?
8. What do you think are the main points in common that you have with the other members of this organisation?

A1.2. Example of interview questionnaire for harm reduction practitioner in Ukraine

1. Can you please describe your work in ENEY/harm reduction organisation? How do you describe harm reduction programmes?
2. Do you think that your programmes relate to HIV? And to human rights? If so, in which way?
3. How do you do your outreach? How do your clients get to know your organisation and the services you provide? Which services do your clients value most?
4. How would you describe your clients? Do they usually have a similar profile and social

background? How do you think they relate to each other? How do they identify with your organisation?

5. How does your programme relate to the public health care sector? Do you work in collaboration with public health officials? Does the Ministry of Health provide any kind of support for your programmes?
6. What are the main difficulties and risks you face when carrying out your harm reduction programmes? In particular in relation to drug users themselves, drug dealers and the police and other law enforcement officers?
7. What are the main advocacy messages of your organisation towards state officials, both political representatives and more concretely in relation to the health authorities?
8. What are the main supporters of the harm reduction programmes that your organisation runs, both internally and externally among donors and other institutions or organisations?
9. Do you relate to other organisations of the wider civil society in Ukraine? Do you collaborate with other organisations, including human rights organisations? How do they regard your work?

A1.3. Example of interview questionnaire for CBO member in Uganda

1. Why was SMUG/other LGBTI organisation created? What objectives does your organisation have?
2. Do you think you belong to a community? If so which community or communities? What makes a community in your opinion?
3. Do you feel safer or more vulnerable now that you belong to this LGBT organisation? What are your main fears now and how different are they to the ones you had before entering the organisation?
4. What do human rights mean to you personally? What human rights matter to you most and why? What has changed in your life since you got to know that you have rights?
5. Why are LGBTI people discriminated against in Uganda? What role do you think political, religious and social leaders play in this discrimination? Does HIV play also any role in this discrimination?
6. ***[Mostly for LGBTI leaders]***: How important is HIV in the work of your organisation, in terms

of services, attraction of members and in advancing the human rights of LGBTI people and vice versa, how has the work for the human rights of LGBTI people contributed to better responses to HIV among LGBTI people?

7. **[Mostly for LGBTI leaders]:** Why has the debate about homosexuality been given so much attention internationally? What did that mean for LGBTI groups? Did this attention strengthen them, weaken them, or expose them?
8. What does the term MSM meant to you? Do you consider yourself as an MSM, or an LGBTI person? What are the differences in your view?
9. **[Mostly for LGBTI leaders]:** How important has been the support of donors for LGBTI organisations, the issues they focus on and the strategies they follow?

A1.4. Example of questionnaire for interview in El Salvador (HIV activists)

1. How has the human rights system contributed to the HIV movement in El Salvador? Do you think it still has a role?
2. What contribution do you think the judicial case against the ISSS for not providing treatment to HIV has made to the HIV response and in the way the movement of people living with HIV has evolved?
3. To what extent has obtaining access to ARV facilitated or hindered the battle for other human rights of people living with HIV, for instance right to education or work or freedom from discrimination?
4. What has become of the movement of people living with HIV in El Salvador today? How has it evolved and what prospects do you see for it?
5. Do you consider that there is a community of people living with HIV in El Salvador? What do you think the characteristics of this community are?
6. How do people living with HIV interact with other populations of people affected by HIV, like men who have sex with men or transgender women? Especially when there could be overlaps between various communities.
7. How has public perceptions around people living with HIV evolved, what are the main reasons in your view for this evolution?

8. How did civil society organisations position themselves before and after the judicial case?
How did the decision impact on these organisations and on the way in which civil society organised around HIV?
9. How do you see the role of donors in the HIV response in El Salvador? How important have human rights been in their approach to supporting the HIV response?
10. How have El Salvadoran governments treated the issue of HIV since the late 1990s what place have they had for human rights in relation to the HIV response?

Appendix 2: Information sheet and consent form for field research interviews

INFORMATION SHEET

A STUDY ON THE IMPACT OF HIV ON COMMUNITIES

You are being invited to take part in a research study. Before you decide whether or not to take part, it is important for you to understand why the research is being done and what it will entail. Please take time to read the following information carefully.

WHAT IS THE PURPOSE OF THE STUDY?

This study is part of academic research for a thesis on the interaction between HIV and communities, particularly from the point of view of human rights. I will be interviewing some people directly affected by HIV, representatives from the communities where they live and decision makers in the HIV response. For that, I have chosen several locations scattered across Africa, Europe and Latin America. The study will take a couple of years to complete.

WHY HAVE I BEEN INVITED TO PARTICIPATE?

You have been invited to participate because of your knowledge about how HIV impacts in your community (adjust to each informant).

DO I HAVE TO TAKE PART?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time without giving a reason.

WHAT WILL HAPPEN TO ME IF I TAKE PART?

I will be asking you some questions about HIV and your community. It will take around 1 hour. We will talk privately in an interview format. I will record our conversation, but your name will not be on the tape. I will keep your contact details in a separate folder in my computer, protected by a password and coded so that nobody can link your identity with the interview that was recorded. You can refuse to answer any particular question. You can also stop the interview at any time and ask to erase the recording at any time during the interview.

WHAT ARE THE POSSIBLE BENEFITS OF TAKING PART?

I have to emphasise that there are no direct benefits for you if you take part in the study. But hopefully, your answers will help others understand the impact of HIV on people and the communities they live in.

WHAT WILL HAPPEN TO THE RESULTS OF THE RESEARCH STUDY?

Some of your answers will be used for my PhD thesis. It is unlikely that you will see your exact answers. It will not be made public, but if you want a copy I will send you one.

WHO IS ORGANISING AND FUNDING THE RESEARCH?

I am carrying out this research as a student of the University of Sussex, but this trip is being carried out as part of my work at the International HIV/AIDS Alliance.

The research has been approved by a Cluster-based Research Ethics Committee (C-REC) at the University of Sussex.

CONTACT FOR FURTHER INFORMATION

My contact details are as follows: Enrique Restoy, 5 Wanderdown Close, Ovingdean, Brighton BN2 7BY. Tel: +44 1273302507. Email: erestoy@aidsalliance.org

If they have any concerns about the way in which the study has been conducted, please contact the Cluster-based Research Ethics Committee (C-REC) on c-recss@sussex.ac.uk

THANK YOU

Thank you very much for your time to read this sheet.

DATE

CONSENT FORM

I am happy for Enrique Restoy to use my answers to the questions he has asked me for research/academic purposes. I provide authorisation for Enrique Restoy to interview being fully aware of the use of how my answers are going to be use. I also understand that I can terminate this interview at any time and the recording erased if I so wish.

(date) at (place)

I consent to the processing of my personal information for the purposes of the research study. I understand that such information will be treated strictly confidential and handed in accordance with the Data Protection Act 1998 of the United Kingdom.

Name:.....

Signed..... Date.....

Address.....

.....

Further information / restrictions:

.....

.....

.....

.....

Appendix 3: Summary of international human rights norms and commitments related to HIV and human rights

Table A3.1: Summary of international human rights norms of relevance to HIV

Universal Declaration on Human Rights (1948)	Declaration adopted by the UN General Assembly. Among other rights, the Declaration enshrines that rights are universal for all people and right to life and the right to a standard of living adequate for the health and well-being of themselves and their family.
International Covenant on Economic, Social and Cultural Rights (1966)	The covenant recognizes the right of everyone to the enjoyment of the highest attainable standard of physical and mental health. Among other steps to be taken by states are: for the prevention, treatment and control of epidemics; and to assure all medical service and medical attention. The Covenant also states the right of everyone to an adequate standard of living for them and their families.
International Covenant on Civil and Political Rights (1966)	The covenant reaffirms the right to life, liberty and security; the right to non-discrimination; that no one shall be subjected to arbitrary or unlawful interference with privacy; and the right to freedom of expression and association.
Convention on the Elimination of All Forms of Discrimination Against Women (1979)	The convention provides the basis for realising equality between women and men, through ensuring women's equal access to, among others, health. The Convention affirms the reproductive rights of women.
Convention on the Rights of the Child (1989)	The Convention protects children's rights by setting standards in health care; education; and legal, civil and social services.

Source: Author from UN Treaty collection²⁰³

²⁰³ UN Treaty Collection, www.un.org, accessed on 8 September 2013.

Table A3.2: Summary of international commitments on HIV and human rights

2011 Political Declaration on HIV/AIDS: Intensifying Our Efforts to Eliminate HIV/AIDS	<p>Adopted by consensus at UN General Assembly.</p> <p>Political Commitment that reaffirms 2006 and 2001 Declarations on HIV and AIDS (below), including:</p> <p>Commits to HIV strategies that promote and protect human rights</p> <p>Commits to promote and protect all human rights with particular attention to all people vulnerable to and affected by HIV.</p> <p>Pledges to eliminate gender inequalities and gender-based violence.</p> <p>Commits to review, as appropriate, laws and policies that adversely affect a successful, effective and equitable response to HIV.</p> <p>Commits to human rights HIV responses that address the specific vulnerability of: young people; children (especially child girls); mobile and migrant populations; workers and their families; people with disabilities.</p>
2006 Political Declaration on HIV/AIDS	<p>Adopted by consensus at UN General Assembly. Political Commitment that reaffirms that the full realization of all human rights and fundamental freedoms for all is an essential element in the international response to HIV.</p>
2001 Declaration of Commitment on HIV/AIDS	<p>Declaration adopted by consensus at UN General Assembly. Political Commitment that sets targets to eliminate all forms of discrimination and to ensure the full enjoyment of all human rights and fundamental freedoms by people living with HIV and vulnerable groups.</p>
2010 Millennium Development Goals Resolution	<p>UN General Assembly Resolution. Political Commitment that acknowledges human rights as a pillar of the UN and essential to achieving the Millennium Development Goals -MDGs (among which MDG 6: Combat HIV/AIDS, Malaria and other diseases).</p>
Human Rights Council Resolution 12/27/2009	<p>Resolution on The Protection of Human Rights in the Context of HIV and AIDS. Recommendations to UN member states. It calls on states to ensure respect, protection and fulfilment of human rights in the context of HIV and urges states to: eliminate laws that hinder the HIV response.</p>

Source: Author from UN Treaty collection.²⁰⁴

²⁰⁴ UN Treaty Collection, www.un.org, accessed on 8 September 2013.